THERE'S NO PLACE LIKE HOME:

A National Study of How People with Intellectual and/or Developmental Disabilities and Their Families Choose Where to Live

CQL | The Council on Quality and Leadership

The Arc

About The Arc

The Arc is the oldest and largest national nonprofit organization supporting people with intellectual and/or developmental disabilities (I/DD). Our mission is to promote and protect the rights of people with I/DD and actively support their inclusion and full participation in the community. The Arc advocates at the local, state, and federal levels for public policy that supports people's right to live and participate in the community with access to the supports and services they need. Our network of more than 600 chapters provides housing and residential supports, helps people with I/DD find and retain jobs, assists students to get the special education services they need to be successful, and supports adults to live full lives of their own choosing in the community and plan for the future.

About CQL | The Council on Quality and Leadership

CQL | The Council on Quality and Leadership is an international not-for-profit organization dedicated to the definition, measurement, and improvement of personal quality of life for youth, adults, and older adults with intellectual and developmental disabilities, and psychiatric disabilities. Since 1969, CQL has demonstrated international leadership in developing progressive measures and indicators of quality in services and supports, personal quality of life outcome measures, and measures of social capital and social determinants of health. We provide a range of services, products and tools to enhance the capacity of individuals, organizations and communities to achieve person-centered excellence. CQL offers accreditation, training, certification, research, and consultation services to agencies that share our vision of dignity, opportunity, and community for all people.

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EXECUTIVE SUMMARY

Executive Summary

The deinstitutionalization of people with intellectual and/or developmental disabilities (I/DD) has reached an all-time high, with the majority of people with I/DD living in community-based settings. Community living is not only preferred by people with I/DD, it is also more cost effective and results in increased positive outcomes across almost all quality of life domains, improved health and safety outcomes, and increases in community participation, relationships, strengthened family contact, and self-determination.

Currently, around 75% of adults with I/DD live with a parent or other caregiver and are not connected to publicly available services and supports. In addition, nearly one-million households have a caregiver over the age of 60. As a result, aging parents and family members frequently serve as unpaid primary caregivers for their family member with I/DD. Many of these families worry about what will happen when they are no longer able to provide their family member with I/DD support, including whether their family member will have to live somewhere they do not want to live. To address these concerns, it is important and necessary for people with I/DD and their families to plan for the future. However, more than half of families have indicated that they do not have a plan for the future.

The Arc of the United States sought to better understand how people with I/DD and their families make decisions about where to live, outside of the family home. As such, the aims of this study were to increase knowledge of housing decision-making and identify barriers to housing decision-making for people with I/DD. To do so, we conducted a two-part mixed method study. The first part of this study included a national online survey of people with I/DD and family members of people with I/DD; the survey included both quantitative and qualitative items. The second part of this study included in-person nominal group technique (NGT) sessions throughout Illinois. NGT is a participatory action research method which includes structured brainstorming similar to a focus group, except it is more inclusive, accessible, collaborative, and reduces the power dynamics often involved in research. In total, 726 people participated in this study (377 people with I/DD (51.93%), 349 family members of people with I/DD (48.07%)), representing 45 states and the District of Columbia.

Findings revealed that although there were many reasons people with I/DD moved from their family homes, or moved across residential settings, most commonly people moved as a result of a need for more support, family members having difficulty caring for their loved one, a desire for more independence, or emergency placements resulting from health or safety issues. People with I/DD and family members of people with I/DD often completed rigorous research to determine which options they had available to them; however, information was difficult to find and there was a general lack of resources. In addition, most people with I/DD, especially those with higher support needs, had few options to choose from as a result of an underfunded and inadequate service system. In addition, most of the time family members made the decision about where their family member with I/DD would live on their behalf, sometimes while consulting them, but other times without.

In their current homes, people with I/DD faced limited opportunities, a lack of true community inclusion, and a plethora of provider house rules. A lack of choices, a lack of community integration, restrictive provider rules, and poor relationships with roommates or housemates all decreased people's satisfaction with where they lived. Factors that increased people's satisfaction with their homes included safety, independence, community inclusion, meaningful activities, and the quality of services and supports people received.

As a result of these wants and needs, the overwhelming majority of people with I/DD as well as family members wanted people with I/DD to live in their own homes or apartments. People with I/DD also dreamt of having opportunities to learn new skills, such as cooking or cleaning, having more independence, being able to see their friends whenever they wanted, having a physically accessible home, and being treated with respect.

The findings from our study have wide implications and, as such, we offer a number of recommendations for both policy and practice. While all of the themes of the report represent opportunities for improvement, we highlight a number of key recommendations, including the need for a centralized place for information and resources; eased system navigation and transparency; an expanded and adequately funded community infrastructure; increased attention to quality including person-centered practices and rights; and, facilitation of opportunities and choice-making opportunities for people with I/DD. While a large number of structural and cultural changes are necessary, these changes will improve the quality of life of people with I/DD.

BACKGROUND

Background

Until the last quarter of the twentieth century, most people with intellectual and/or developmental disabilities (I/DD) lived in institutions.[1] Families that had a child with I/DD were commonly advised to put their child in state hospitals or other facilities rather than raising them at home. However, after decades of fighting for deinstitutionalization, most people with I/DD now live in the community.

INSTITUTIONALIZATION, DEINSTITUTIONALIZATION, AND COMMUNITY LIVING

Systematic institutionalization of people with disabilities, especially those with I/DD and mental health disabilities, began in the 18th century, first in Europe and then in the United States, as a moral approach to care (Aschbrenner, Grabowski, Cai, Bartels, & Mor, 2011; Geller, 2006; Trent, 1994). Institutions, which were framed as 'schools,' were established across the United States in response to a 'moral' problem – to train people with I/DD to be moral, productive, and useful members of society (Sacks, 2009; Trent, 1994). However, as institutions grew and expanded, it became harder to teach larger numbers of people; for this reason, institutions shifted from their original educational intent to instead serve a custodial purpose, wherein people were managed rather than educated (Carlson, 2010; Trent, 1994). Early institutions often had horrible conditions, treated people like cattle, and stripped them "of every vestige of human decency" (Davis, Fulginiti, Kriegel, & Brekke, 2012, p. 262). In addition, in the aims of advancing scientific theories and reducing 'negative' behaviors, it was not uncommon for facilities to utilize harmful techniques on the people who lived in institutions, such as shock therapy, frontal lobotomies, and forced sterilization (Geller, 2006).

Institutions for people with I/DD continued to grow in size and scope, despite being overcrowded and offering poor care, until a combination of advocacy from people with I/DD and family members, a shift in public consciousness regarding segregation and people with I/DD, and a number of policy and legislative changes spurred the deinstitutionalization movement in the 1950s and 1960s. Persistent self-advocates with I/DD as well as advocacy by family members significantly impacted institutional reform and resulted in a growth of community alternatives. John F. Kennedy's Panel on Mental Retardation[2] in 1961 strongly advocated for downsizing institutions and expanding community alternatives (Braddock, 2007). Important legal rulings, such as *Wyatt v. Stickney*, resulted in sweeping reforms of state facilities and set standards of care. Laws prohibiting discrimination based on disability, including the Rehabilitation Act of 1973 and the American with Disabilities Act (ADA), coupled with cases such as *Olmstead v. L.C.*, reinforced the "integration mandate," the right of people with disabilities to be in the community. The Arc has historically been deeply involved in groundbreaking disability rights litigation and helped lead efforts to transform state service systems for people with disabilities, ensuring that people with I/DD have access to education and life in the community.

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[1] Intellectual and/or developmental disabilities include disabilities such as Down syndrome, autism spectrum disorder, fetal alcohol spectrum disorder, intellectual disability, and others.

[2] Although now considered outdated and pejorative, "Mental Retardation" was the official name of the Panel. Today it is considered best practice to use I/DD instead.

Changes to long-term services and supports (LTSS) have also contributed to a decreased institutional census. LTSS are services and supports that help people with activities of daily living and instrumental activities of daily living over an extended period, rather than acute care. The United States authorized the Medicaid Home and Community Based Services (HCBS) waiver program in 1981 as an alternative to intermediate care facilities for individuals with developmental disabilities (ICFDD). HCBS waivers allow states to create and expand community LTSS tailored to populations that would typically require institutional care. Surpassing ICFDD funding in 2000, Medicaid HCBS waivers are now the largest funding stream for of LTSS for people with I/DD in the United States (Braddock, Hemp, Tanis, Wu, & Haffer, 2017).

Finally, deinstitutionalization has also been spurred by not only the preferences of people with I/DD but also the benefits of community-living for people with I/DD. Compared to institutional settings, people in the community, including those with higher support needs, have increased positive outcomes, including self-determination, larger social networks, increased participation in community life, and increased choice (Beadle-Brown et al., 2016; Friedman, in press-a; Hemp, Braddock, & King, 2014; Lakin, Larson, & Kim, 2011; Larson, Lakin, & Hill, 2013; Larson & Lakin, 1989; Mansell & Beadle-Brown, 2004). In addition, community living is significantly more cost-effective than institutional care (Braddock et al., 2017). All of these factors have resulted in state institutional censuses decreasing annually since its peak in 1967, with the majority of people with I/DD moving to community-based settings. (Braddock et al., 2015). In fact, over the last 50 years, the state institutional census has decreased 85%, an average of 4% per year (Braddock et al., 2015; Braddock et al., 2017).

A LACK OF FAMILY SUPPORTS

Currently, about 75% of adults with I/DD live with their parents or other family members, the majority of which are not receiving formal services or supports (Braddock et al., 2015; Larson et al., 2001). As such, many parents and family members serve as the unpaid primary caregiver for their loved one with I/DD. In the United States, there are nearly one-million households in which an adult with I/DD is living with caregivers 60 or older (Braddock et al., 2017). Half of caregivers are older than 50, and nearly 10% are 75 or older (National Alliance for Caregiving & AARP, 2015). According to Anderson et al. (2018), 52% of caregivers spend at least 40 hours a week supporting their family member with I/DD. Anderson et al. (2018) also found that most caregiver have serious concerns about the future, for themselves and for their child with I/DD. One of the most common concerns was that a family member with I/DD will have to live somewhere they do not want to live, such as a nursing home or institution (Anderson et al., 2018). Unfortunately, more than half of families in the study also had no plan in place for what will happen when the caregiver either passes away or is no longer able to provide care.

These families need encouragement and support to plan for what will happen as people with I/DD—and their caregivers—age. For these reasons, The Arc's Center for Future Planning aims to support and encourage adults with I/DD and their families to plan for the future. The Center provides reliable information and assistance to individuals with I/DD, their family members and friends, professionals who support them, and other members of the community on areas such as person-centered planning, decision-making, housing options, and financial planning. In 2018, The Arc began research aimed at helping better understand the challenges families face when making plans around future homes and how families make decisions about future homes. The Center's hope is that this research will guide future practical resources for people and families to help them as they identify potential home settings, outside of a family home.

AIMS & METHOD

Aims and Method

The Arc of the United States sought to better understand how people with I/DD and their families make decisions about where to live, outside of the family home. The aims of this study were to increase knowledge of housing decision-making and identify barriers to housing decision-making for people with I/DD. We approached these aims utilizing a mixed methods design. Our study included not only a national quantitative and qualitative online survey of people with I/DD and family members of people with I/DD (Part I) but also in-person nominal group technique (NGT) sessions (Part II), a qualitative and quantitative participatory action research method. The combination of methods not only allows data from a larger and more diverse sample, it also serves as a form of triangulation of the data.

PART I: ONLINE SURVEY

The first part of this study was a national online survey with people with I/DD and family members of people with I/DD about housing decision-making and residential services. A total of 615 people participated in Part I of this study. Of the 615 participants, 308 (50.01%) were people with I/DD, and 307 (49.92%) were family members of people with I/DD. The following settings were represented in the sample: own home or apartment (50.66%), supervised group home or apartment (25.74%), home of a family member (10.16%), planned community or campus where only people with I/DD live (4.92%), institution (including ICFs and nursing homes; 2.30%), home of a friend (2.13%), school dormitory (1.31%), host home (0.82%), homeless (0.33%), and other (1.64%). 41.6% of participants reported they (if a person with I/DD themselves) or their family member with I/DD did not live with other people with disabilities. Those people who lived with other people with disabilities, lived with an average of 4.32 people with disabilities (SD = 8.88). Of those who lived with others, 75.95% of people lived with between one and four other people with disabilities, 13.92% lived with between five and eight, 5.06% lived with between nine and 12, 2.22% lived with between 13 and 15, and 2.85% lived with 16 or more people with disabilities.

Part I demographics are presented in *Table 1*. The most prevalent disabilities represented in Part I were intellectual disability (59.67%), autism spectrum disorder (34.47%), and cerebral palsy (16.59%). Participants represented 45 different states and the District of Columbia, with only Delaware, Idaho, Kansas, Mississippi, and Wyoming not being represented in the sample. Of the 615 participants, 43.28% were from suburban areas, 33.33% urban areas, and 23.38% rural areas. The majority of participants were Women (66.50%), and White (80.65%). The most prevalent decision-making authorities were making decisions with support from people they trust (48.60%) and guardians (32.51%). The most prevalent primary communication method was verbal/spoken language (87.36%). The majority of people with I/DD or family members with I/DD received support to take care of themselves or their home (76.67%) but how much support they received per day on average varied. The majority of participants in Part I reported they (if a person with I/DD themselves) or their family member with I/DD received government funded services (74.67%).

PART II: NOMINAL GROUP TECHNIQUE

The second part of the study was a series of NGT sessions with people with I/DD and family members of people with I/DD. NGT is a structured brainstorming technique similar to a focus group, except it is more inclusive, accessible, collaborative, and reduces the power dynamics often involved in research (Owen, Arnold, Friedman, & Sandman, 2016).

Illinois served as the location for the NGT sessions. While community inclusion is arguably lacking in every state, the issue is especially problematic in Illinois, where the HCBS service system is in particular need of quality improvement. Illinois is ranked 50th in the nation in terms of placement of people in community-based residential settings of six or less (Braddock et al., 2017). As a result of this climate and these barriers, Illinois was used to examine the barriers and facilitators people with I/DD and their families encounter when seeking information about housing options, relocation, and satisfaction.

A total of 111 people participated in Part II of this study. Of the 111 participants, 69 (62.16%) were people with I/DD, and 42 (37.84%) were family members of people with I/DD. Family members were mostly parents (85.71%) but also included siblings (7.14%) or other relatives (7.14%). The following settings were represented in the sample: supervised group home or apartment (40.54%), planned community or campus where only people with I/DD live (27.93%), home of a family member (18.02%), own home or apartment (9.01%), institution (including ICFs and nursing homes; 4.50%), and other (1.80%).

Part II demographics are presented in *Table 2*. The most prevalent disabilities represented were intellectual disability (63.64%), autism spectrum disorder (21.82%), and cerebral palsy (14.55%). Of the 111 participants, 51.40% were from suburban areas, 30.84% urban areas, and 17.76% rural areas. The majority of participants were Women (60.91%), and White (75.70%). The most prevalent decision-making authorities were guardians (53.21%) and making decisions with support from people they trust (31.19%). The most prevalent primary communication method was verbal/spoken language (86.24%). The majority of people with I/DD or family members with I/DD received support to take care of themselves or their home (92.66%), with most receiving 24/7 around-the-clock support (66.67%). The majority of participants in Part II reported they (if a person with I/DD themselves) or their family member with I/DD received government funded services (92.52%).

RESULTS:
ONLINE SURVEY (PART I)

Results: Online Survey (Part I)

The first part of this study was a national online survey with people with I/DD and family members of people with I/DD about housing decision-making and residential services. A total of 615 people participated in Part I of this study.

FINDING RESOURCES AND SYSTEM NAVIGATION

As far as where participants found information about different housing options and what resources were most helpful to them, most experiences paralleled those of one participant who said, “there is no one organized place for information.” Some participants found resources or information through government agencies such as through state developmental disabilities departments, the department of housing and urban development (HUD), or the department of social services. Others turned to Centers for Independent Living, county community mental health agencies, or Microboards and cooperatives. (Microboards are a small group of people, including people with I/DD, family, and friends that come together to create a non-profit.) More commonly, participants described informal networks as sources of information. Frequently, people found information via word of mouth, including by networking with friends, family, and parent advocacy groups. Some people utilized social media, such as Facebook groups, or disability-specific resource networks to gather information. Disability fairs, conferences, and workshops were seen by some as a fruitful way to gather information about housing options. Other people got information about their options through case managers, social workers, support coordinators, or directly from agencies. A large number of participants also described doing research to find information to assist them in their decision-making. People often searched the newspaper or used the Internet to find information. For example, accessible housing registries and affordable housing lists were used to help guide decision-making. Other people used apartment or rental websites, such as Craigslist, or reached out to real estate agents to gather information.

HOW PEOPLE DECIDED WHERE TO LIVE

When asked how they decided where they or their family member with I/DD should live, many participants responded that they did not have a choice – the home where the person with I/DD lives was the only option available to them, or they were placed by external forces and did not have a choice. Others spoke to the limited choices available to them, particularly depending on state funding, affordability, availability, or location. A number of people accepted the first available spot or chose between the best of only two options. Some participants mentioned not being able to find any residential homes, especially in rural areas. A few participants also described trying a variety of residential options, such as group homes, but having them fail, which limited their remaining possibilities.

> “*It was this, or an institution, or dead*”
>
> — Person with I/DD

In contrast to those that had limited choices, people that had choices when it came to deciding where to live emphasized looking for features such as how close the home was to transportation, services and supports, grocery stores, nature, banks, and family members. Others looked for safe homes and neighborhoods, accessible houses and communities, and places that felt like friendly communities for people with disabilities. Many participants spoke specifically of wanting to find a place in the community or the need for independence. Some participants highlighted the reputation of the agency and the services it offered, the quality of its staff, the choices it allowed, and its culture and feel. Decisions were often also impacted by touring a range of settings. A few participants also said their past experiences informed their decisions.

A number of participants described who decided where the person with I/DD would live. For some people, this decision was significantly impacted by the need for an emergency placement, (*e.g.,* after the death or illness of a parent caregiver). Many participants acknowledged parents were the decision-makers, either with or without the input of the person with I/DD. For example, one parent described that they believed their son's limited exposure to options outside of their family home made including him in decision-making difficult, as they believed his choices would not be informed. A few family members described coming together with other families to buy a house for their adult children to live in. Sometimes, it was a case manager, representative payee, or court guardian who made the decision, while in other instances residential providers decided about the placement of people. Still other people consulted with friends or spouses about placement, or people with I/DD made decisions on their own.

AVAILABLE OPTIONS AND CHOICES

Options to Choose From

Participants were asked which types of housing settings were available to them when looking for their or their family member with I/DD's current residence. According to participants, the options that were reported most were their own home or apartment, a supervised group home or apartment, and a home of a family member or friend, while the least reported options were a host home, school dormitory, and 'other' settings (*see Table 3*). However, the majority of participants (56.76%) reported the only option they had was the setting where they or their family member with I/DD currently lived (*Table 3*). It may be that this was because they truly had no other choices, that they were not interested in exploring different options, and/or that they had difficulty finding resources about other available options.

Both people with I/DD and family members of people with I/DD reported that their own home or apartment, a supervised group home or apartment, and a home of a family member or friend were the options that were most available to them (*Table 3*). However, people with I/DD were more likely to report having the options of their own home or apartment than family members, while family members were more likely to report having the options of supervised group home or apartments, home of a family member or friend, and a planned campus or community where only people with I/DD lived I/DD. In addition, people with I/DD were more likely than family members to report that their only option was the current setting where they lived; 60.99% of people with I/DD reported their only option being their current one, while 52.38% of family did.

Choosing Where to Live, with Whom, and in What Neighborhood

Across the online survey participants (**FIGURE 1**), 80.25% reported they and/or their family member chose ***where to live***, while 16.88% did not choose where to live, and 2.87% answered 'other'. Those that answered 'other' commented that they were only able to choose from very limited options, such as what settings had openings, especially if they had been on long waiting lists, or what worked with their limited financial resources. A few others commented that their trustee or family members chose for them, either with or without their permission.

Of online survey participants, 68.90% reported they and/or their family member chose ***with whom to live*** (*e.g.*, by themselves or with roommates or housemates), while 29.29% did not choose who to live with, and 1.81% answered 'other.' Those that answered 'other' commented that they selected this answer because they followed staff suggestions regarding housemates or roommates, could not choose because of unique health care needs (*e.g.*, pica), or believed their family member with I/DD should not be able to choose living by themselves. Moreover, one other participant noted their family member originally chose who they lived with, but it would be very difficult to change and make a different decision now.

Of online survey participants, 67.34% reported they and/or their family member were able to choose the ***neighborhood they wanted to live in***, while 29.74% did not choose where to live, and 2.92% answered 'other.' Those that answered 'other' commented that their choices in neighborhood were limited by what they could afford and dependent on openings. A number of participants whose family members with I/DD live on campus settings also commented they selected the campus, not the neighborhood.

Only slightly more than half of survey respondents (54.66%) reported having ***all three choices*** – where to live, with whom to live, and in what neighborhood. People with I/DD were more likely to report having all three choices (where, with whom, and which neighborhood) than family members (59.78% versus 49.43%).

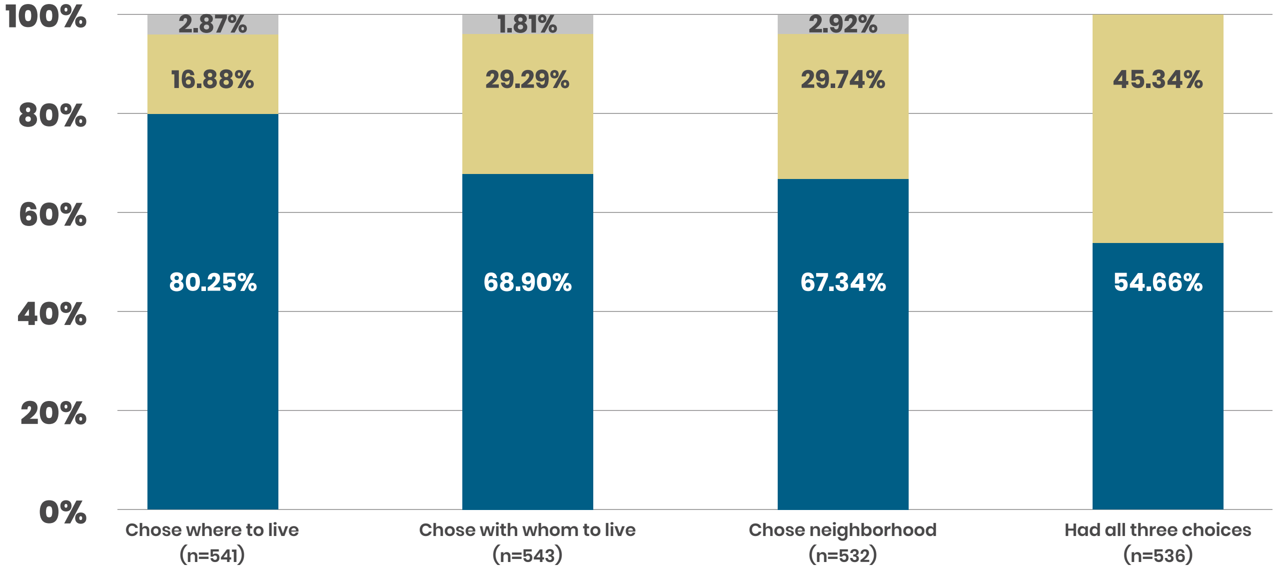

FIGURE 1. Types of Choices Available to Participants.

People with I/DD were slightly less likely than family members to report being able to choose what neighborhood to live in (68.75% versus 70.00%). However, they were more likely to report being able to choose who they lived with (77.17% versus 62.92%; see *Table 4*).

In terms of differences across settings, people who lived in the following settings were most likely to choose ***where to live***: host homes (100%), planned communities or campuses where only people with I/DD live (93.10%), and own homes or apartments (89.38%). People in host homes, own homes or apartments, and home of a family member were most likely to report being able to choose ***who they lived with*** (100.00%, 89.13%, and 75.47% respectively). People in host homes (100.00%), in planned communities or campuses where only people with I/DD live (80.00%), and in their own homes or apartments (79.64%) were the most likely to report being able to choose the ***neighborhood where*** they or the person with I/DD lived. **FIGURE 2** details people that had all ***three choices by setting***.

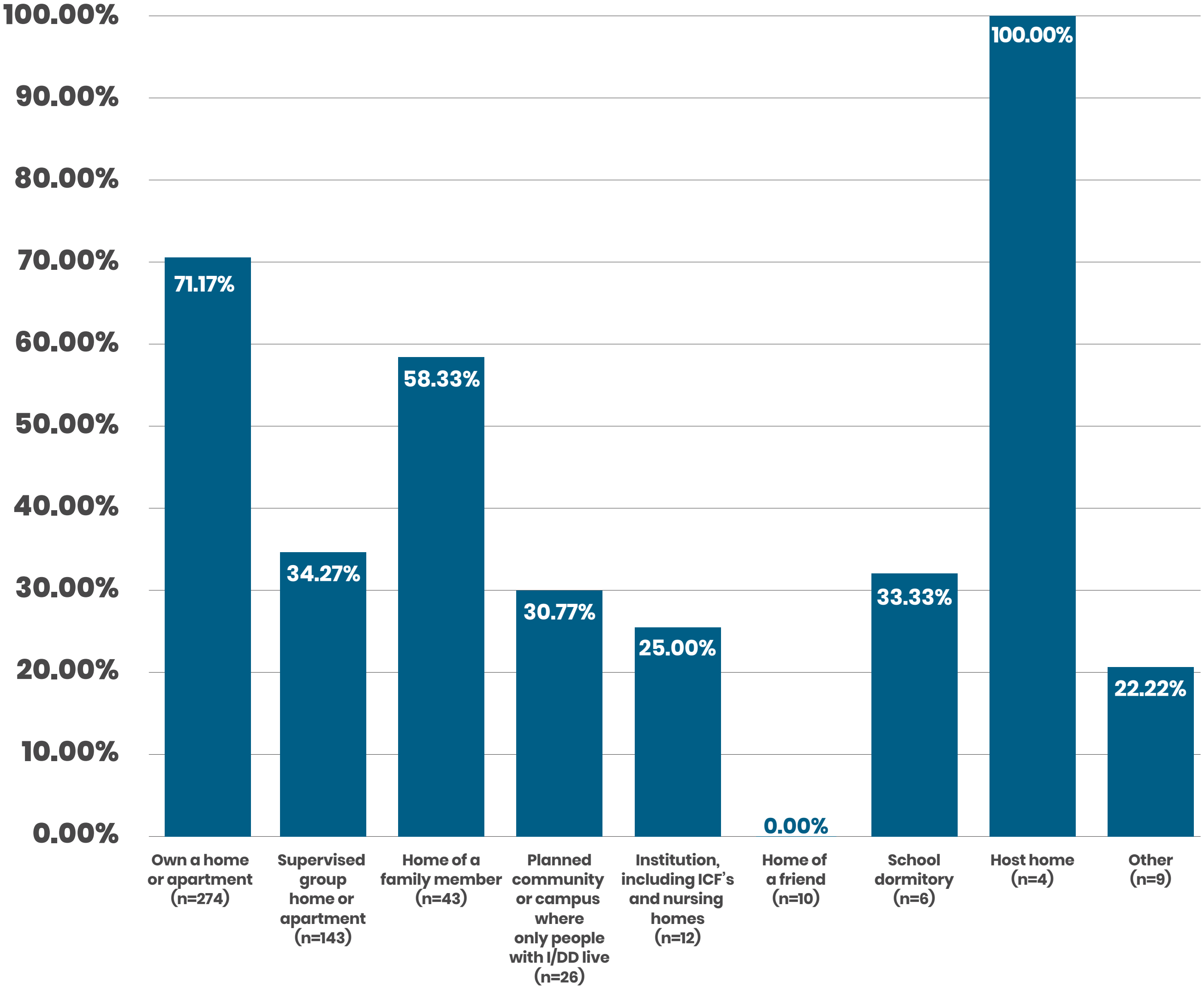

FIGURE 2. Percent of People that Had All Three Choices (Where, With Whom, and Which Neighborhood) by Setting (all participants; n = 532).

MOST IMPORTANT FACTORS IN HOUSING

Participants were asked the five things that were most important to them when deciding where they or their family member with I/DD would live. Although the question was open-ended, we utilized indicator coding to tally and rank the responses. Participants identified the following as important factors regarding the location where they lived: being close to family; a sense of community; being in the community or the ability to go into the community; neighborhood; friendly neighbors; walkable or walking distance; access to transportation; low traffic; safety, security, and freedom from crime; access to public parks or nature; close to work, school, day services, and/or other services; and, close to shopping, places of worship, libraries, doctors, restaurants, etc. They identified the following as important factors related to the housing itself: quality and stability of staff; quality of services and supports; family involvement; the person having their own home or apartment; the person having their own room; the person having their own bathroom; good relationships with roommates or housemates; cost; physical size or space; ability to have pets; clean home; nice home in good condition; access to quality food; accessibility; quiet; activities and things to do; lack of house rules; backyard; building amenities; nice landlord or management; near or with friends or romantic partners, or the ability to make friends or romantic partners; being with similar peers; the availability of constant oversight (24/7 around-the-clock); the culture, including one of respect; the long-term sustainability of the placement; the ability to experience the house first or tour the setting; and availability (*e.g.*, what's available or has open slots). Other important factors included the ability of the person with I/DD to be independent as well as the choice, satisfaction, and/or happiness of the person with I/DD. It should be noted, a few participants reported having no choices.

Those factors that were described most often – ranked as the most important – across the participants were (*see Table 5*):

1. Safety, security, and freedom from crime
2. Cost
3. Location
3. Close to family
5. Quality of services and supports
6. Close to shopping, places of worship, libraries, doctors, restaurants, etc.
7. Quality and sustainability of staff
8. Close to work, school, day services, and/or other services
9. Transportation
10. Activities and things to do.

However, the priorities differed slightly by participant group – if the respondent was a person with I/DD or if the respondent was a family member of a person with I/DD (*see Table 5*).

People with I/DD prioritized:

1. Cost
2. Location
3. Safety, security, and freedom from crime
4. Close to shopping, places of worship, libraries, doctors, restaurants, etc.
5. Transportation
6. Close to family
6. Close to work, school, day services, and/or other services
8. Neighborhood
8. Nice home in good condition
10. Accessibility

Meanwhile, family members of people with I/DD prioritized the following:

1. Safety, security, and freedom from crime
2. Close to family
3. Quality of services and supports
4. Quality and stability of staff
5. Location
6. Cost
7. Activities and things to do
8. Close to work, school, day services, and/or other services
9. Close to shopping, places of worship, libraries, doctors, restaurants, etc.
10. Transportation

SATISFACTION

When participants were asked how happy they were with where they or their family member with I/DD live, 45.14% reported being very happy, 27.34% somewhat happy, 7.58% not unhappy or happy, 9.88% somewhat unhappy, and 10.05% very unhappy (*see Tables 6a and 6b; Figure 3*).

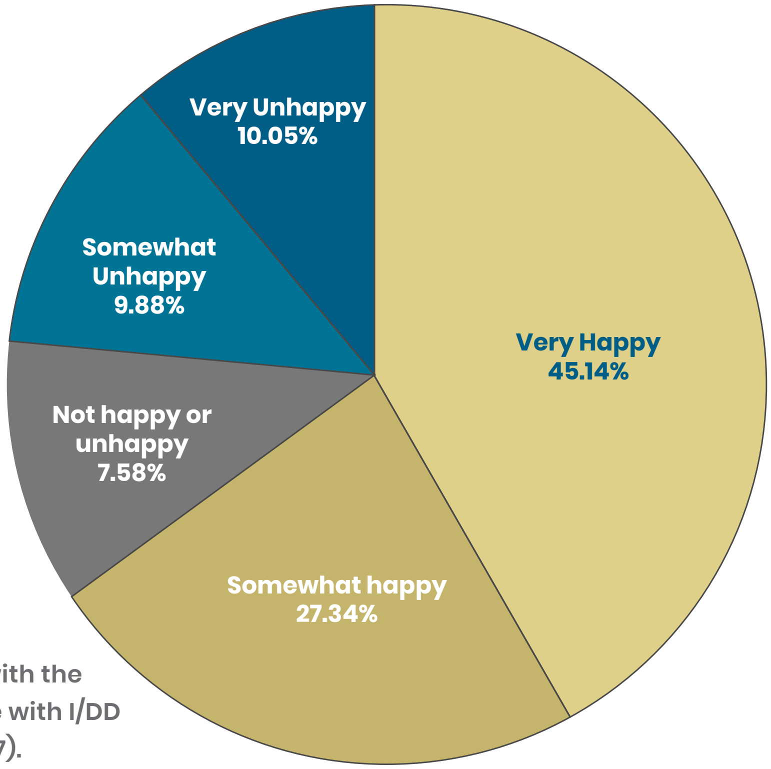

FIGURE 3. Satisfaction with the Current Home of People with I/DD (all participants; n = 607).

Survey participants who were family members of people with I/DD reported being significantly happier than survey participants with I/DD regarding where they/their family member with I/DD lived (see **FIGURE 4**; *Table 6a*). In terms of differences across settings, people in planned communities or campuses where only people with I/DD lived, supervised group homes or apartments, and host homes (all respondents) reported being the happiest, while people who were homeless, lived in a home of a friend, or in a school dormitory reported being most unhappy. However, there were differences between setting and group (people with I/DD versus family members). Family members whose relative with I/DD lived in a planned community or campus where only people with I/DD live were significantly happier with where their loved one lived than people with I/DD who lived in a planned community or campus where only people with I/DD lived (*Table 6b*). People who reported being able to choose where they lived, with whom, and what neighborhood they lived in also reported being significantly happier than people who reported not being able to make those choices.

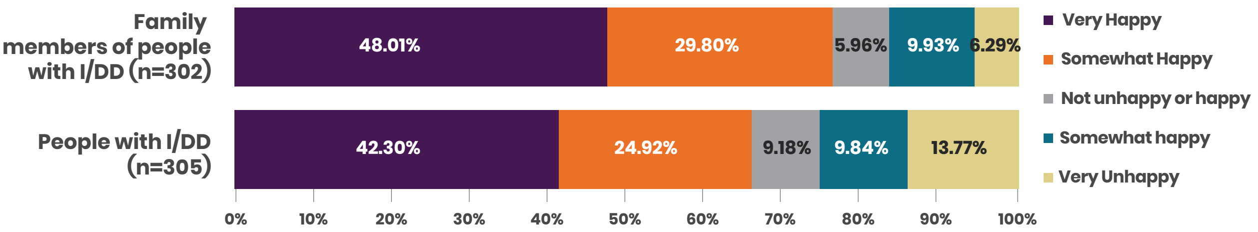

FIGURE 4. Satisfaction with Where They/Their Family Member Lived (all settings) by Participant Group.

Factors that Increased Satisfaction

There were a number of factors that increased people's satisfaction with their housing. Survey participants commented that they liked where they or their family member with I/DD lived because it was safe – they were free from abuse and neglect, there was supervision, and they did not have to worry about people being taken advantage of. Positive aspects of people's homes also included homes being quiet, accessible, attractive spaces, and meeting people's needs. Privacy was also another aspect that positively contributed to people's satisfaction.

In terms of the neighborhoods where their home was located, people appreciated being in walking distance to work, places of worship, and shops and restaurants. Access to public transportation was also described as important, as was the community; while some described a small family-oriented community as making them happy, others spoke of the benefits of a big city.

The agency providing supports, as well as support staff, played a role in people's satisfaction with where they lived. For example, participants spoke about the importance of good staff who treat people with I/DD with dignity and respect. Other participants described favoring agencies that communicated with the family – keeping family members informed and allowing them to be involved.

Relationships also played a significant role in one's satisfaction with where they/their family member lived. Some people described that people with I/DD being able to live with or near their friends or romantic partners was important to them and increased their quality of life. Feeling loved and getting along with others significantly improved people's satisfaction. Others spoke to the benefits of people with I/DD having their own rooms or living on their own.

> *I like knowing it is mine*
>
> — Person with I/DD

Finally, people's opportunities and choices related to their homes also positively impacted the satisfaction of people with I/DD and family members of people with I/DD. Many participants described the importance of people with I/DD being able to make their own choices, having the responsibilities that go along with those choices, having independence and freedom, and not being hindered by rules. A number of participants also described person-centeredness as an important feature of where they/their family member lived. Opportunities to participate in activities, including ones to socialize or have romantic relationships, were also described as benefits of the living setting.

Factors that Decreased Satisfaction

Many of the factors that resulted in increased satisfaction also hindered people's satisfaction when they were not present. For example, many people described being dissatisfied by settings that were physically too small or those that had too many other people. A number of people noted wanting more privacy, including people with I/DD having their own space or living on their own. A lack of accessibility was also a problem for some respondents. Participants also described problematic instances of neglect, violence, lack of cleanliness, and belongings being stolen. Some participants also spoke of how hard noisy settings can be to live in, especially to those people that may be sensitive to, or distressed by, loud noises. Others described problems with landlords, including those who would not do repairs. Many people also detailed living in isolated neighborhoods that not only had a lack of opportunities but also a lack of transportation options. A number of people described their/their family member's neighbors as not safe and the neighborhood having too much crime. These people wanted to live/their family member to live somewhere safer.

Support staff again played a crucial role in people's dissatisfaction with where they lived. Not only was staff turnover described as causing an unstable environment, staff were often described as poorly trained and not qualified to meet the needs of the people with I/DD. A few participants also commented that staff treated people with I/DD like children, talked about them behind their backs, ignored them, and/or made fun of people with I/DD for their disabilities. Family members also described a lack of communication from staff and agencies as problematic. Some participants noted poor agency management and operations also hinder their satisfaction. A few parents stated that constant advocacy was required on their part to ensure their family members with I/DD received the services and supports they needed.

Conflicts with roommates or housemates served as another major source of dissatisfaction according to survey participants. Many people cited drama with roommates/housemates as problematic and wanted to be able to choose their roommates and housemates. Several people with I/DD and family members of people with I/DD described wanting people with I/DD to be able to live with their romantic partners. Other participants noted people with I/DD lived with people a lot older than themselves and that they would prefer peers closer to their age and personality. In addition, people with I/DD and family members described people as being isolated and lonely, having a lack of people to relate to, and feeling like they do not belong. A few people said they missed their family members who lived far away. Other people with I/DD remarked that they felt isolated by neighbors who made fun of them for having disabilities or verbally harassed them.

People also described having a lack of choice, not only regarding the housing options themselves but also the features of where people lived. For example, a number of people with I/DD noted that they wanted to have pets, but pets were not allowed. Others wanted more independence and/or support to develop independent living skills. There was also a need for more activities to participate in, especially to compensate for people being isolated and not going into the community.

People's ability to change to settings that had more space and were in better areas, or of higher quality, were often hindered by their finances. Many reported housing being too expensive and their choices being limited to what was available in their price range, as many people with I/DD have low incomes and scant resources. A few participants with I/DD even described being uneasy about their financial situations and living in constant fear of losing their homes and becoming homeless.

Finally, several participants described a lack of stability as contributing to their dissatisfaction. As parents age, they are not able to support their family member with I/DD as much as before – it becomes too much for aging caregivers. For example, one participant described the person with I/DD not having a stable 'safety net' after the parents are gone.

WHY PEOPLE MOVE ACROSS SETTINGS

Participants were asked how often they moved to a new home, and, if applicable, what precipitated those moves. While 29.61% of participants reported never moving, of those that did move, it was most common to move less often than every 10 years (29.42%; **SEE FIGURES 5 AND 6**). People who lived in a friend's home moved most often compared to other settings.

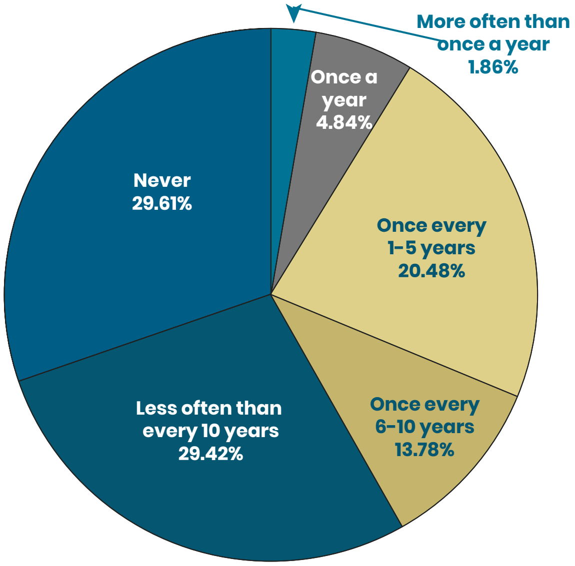

FIGURE 5. Frequency of Moves (all participants, all settings; n = 537).

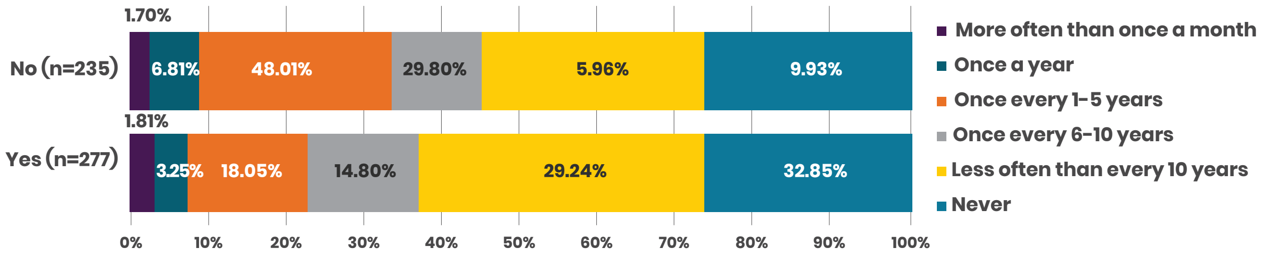

FIGURE 6. Frequency of Moves by People Who Had all Three Choices (Where, With Whom, and What Neighborhood).

There were a wide variety of reasons why people with I/DD moved to new homes, including reasons related to systems changes, family changes, wants and needs, problems, and environmental features. In terms of system changes, some moves were caused by getting off waiting lists for subsidized housing, changes in finances or affordability, or end of leases or landlords selling property. In terms of family changes, moves were caused by declines in a parent's health, parent burnout, or death of a family caregiver. Other people moved by choice. Others moved because of the changing needs of the person with I/DD – because of changing medical, physical, mental health, or accessibility needs – or because their needs were not being met. Some people moved because of agency changes, such as closure of group homes, problems with management, or excessive staff turnover. Some people noted moving because of their wants for more independence and freedom, more space, more socialization opportunities, and to be closer to family and/or friends. Others moved because they wanted or needed an environment that had better public transportation or that was closer to work or school. Finally, a number of people moved because of problems. Abuse, lack of safety, and/or bad living conditions were the reason many people moved. Others moved because of conflicts with roommates or neighbors, or poor treatment by staff. A few participants noted problems with housemates or staff often exacerbated or caused them to participate in risk behaviors or 'problem behaviors' which triggered the need to move.

FUTURE CHOICES

When asked which options were available to them if they were to change their mind about where they or their family member currently lives, slightly more than half of survey participants reported they could choose a new housing type (57.17%) or a new neighborhood (51.43%), while fewer people reported being able to choose a new roommate (29.30%) or new room (23.57%); 1.02% said they had 'other' choices. A sizable percentage of participants said they had no future choices (17.83%; **FIGURE 7**).

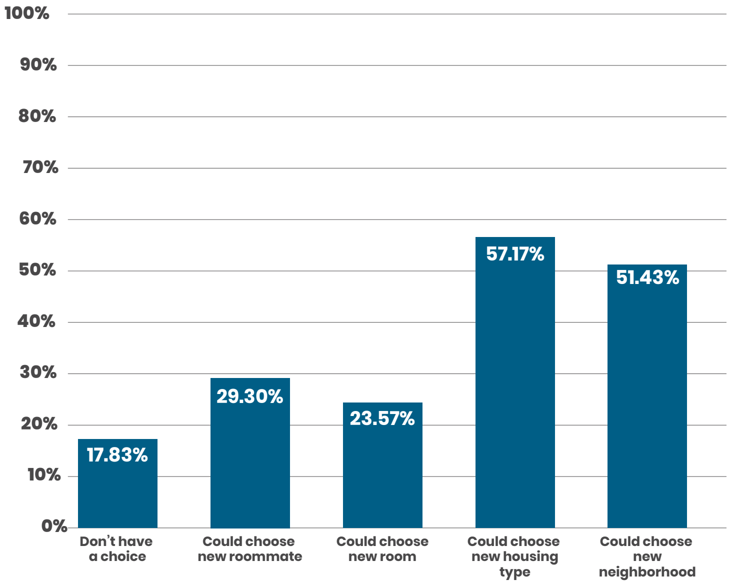

FIGURE 7. Future Choices (all participants, all settings; n = 488).

Differences between people with I/DD and family members as well as differences by setting are presented in *Table 8*. People with I/DD across settings reported being able to pick a new neighborhood more often than family members did (56.22% versus 46.44%). People (both people with I/DD and family members) who lived in a planned community or campus where only people with I/DD live and people who lived in supervised group homes or apartments were most likely to report being able to choose a new roommate. People (both people with I/DD and family members) who lived in a planned community or campus where only people with I/DD live and people who live in the home of a friend were most likely to report being able to choose a new room. People (both people with I/DD and family members) who lived in their own homes or apartments were most likely to report being able to choose a new neighborhood.

We also compared the differences between people with I/DD and family members, while factoring in the settings they currently lived in. People with I/DD who lived in family homes were more likely to say they did not have any future choices compared to family members who had loved ones with I/DD living with them (41.67% versus 13.51%). People with I/DD living in a planned community or campus where only people with I/DD live were less likely than family members of people living in the same setting to report being able to choose a new room (16.67% versus 76.47%) or roommate (16.67% versus 70.59%) but were more likely to say they could choose a new neighborhood (66.67% versus 17.65%).

DREAM HOMES

When asked about their dream living scenario for themselves (if they were a person with I/DD) or their family member with I/DD, a number of participants described the physical design of the settings. For example, people spoke about wanting a larger home or bigger bedroom. Many wanted their own room or space, including a private bathroom and sitting area. Participants dreamt of having a backyard, laundry room, swimming pool, exercise room and/or garden. Many people wanted to be able to have pets. A few participants dreamt of a house that was accessible enough for them to fully get around, such as accessing their closet or having a less-steep ramp that did not require being pushed. Some participants with I/DD wanted an elevator in their dream home. Others spoke of settings that were designed so people with I/DD could age in place, including those people with I/DD and dementia. A number of people wanted the home to be clean and updated. Still others wanted technology to be leveraged so the home was energy efficient or even automated, such as a smart home.

Participants spoke not only of the physical spaces but also the culture of their dream homes. In their dream scenarios, people with I/DD would be valued, respected, and loved. The person with I/DD would be an integral member of the house and community, rather than a 'facility resident.' The culture would also not be custodial in nature but rather present people with lifelong and continuous opportunities for learning, growth, and independence. A few people specifically mentioned the importance of these spaces having no discrimination or ableism. People also wanted a place where they felt secure. Not only did they want continuity – a place "where things aren't constantly changing" – but also to feel financially secure – "a house no one can take away." A few people mentioned their dream homes were affordable and had reasonable rents or places they were able to buy instead of rent.

Dream homes were cited for also including supports; however, people felt these supports would be provided in a way that was as natural as possible. People's dream homes also presented them with opportunities and activities. People wanted alone time but also plenty of activities to participate in, including those related to employment and making and maintaining friends.

In terms of who people with I/DD would live with in their dream homes, some people wanted to live alone while others wanted to live with roommates or their romantic partners. The important part for people with I/DD was being able to choose who they lived with. People wanted housemates and roommates that were similar to themselves in terms of age and interests. A few family members said it was important for people to live with a mix of people with and without disabilities, while others said their dream for their family member with I/DD was an intentional community where people with I/DD and family members of people with I/DD live together, modeled after a retirement village.

> “*[My dream home is] a place where there are people who like me*”
>
> — Person with I/DD

In terms of location, while a very small handful wanted to live in international cities, the majority of people described their dream home as being near family and friends and having amenities in the building and in walking distance. For example, people wanted to live near a library, banks, shopping, places of worship, and recreation sites. People wanted there to be community activities, including outdoor and physical activities, and community gardens. Access to transportation, both affordable public transportation and accessible private transportation, was an important part of where one lived. So, too, was the friendliness of the neighborhood – people wanted good neighbors and to be part of an inclusive community. People also wanted the neighborhood to be safe and have less crime, and to feel safe when walking outside.

Finally, staff also played a role in dream housing scenarios. People wanted well-trained and stable staff, with significantly less turnover. In fact, one participant mentioned in their dream scenario staff would be paid at least 150% of the minimum wage and receive benefits. Some people described wanting to be able to select their staff, while others wanted live-in staff. Staff were described as needing to be passionate and attentive to the needs of people with I/DD. One parent commented that “right now a lot of staff time is taken up with direct care and not focused on quality of life or growth of independent skills.”

Dreams by Group and Setting

The setting people dreamt of living in most was their own home or apartment (61.80%), followed by a supervised group home or apartment (14.36%), and home of a family member or friend (11.92%; *Table 9a* and **FIGURE 8**). However, dreams differed by participant group (person with I/DD versus family member of person with I/DD; **FIGURE 9**). Although both people with I/DD and family members of people with I/DD had own homes or apartments as their number one setting, it was overwhelmingly the preference for people with I/DD (78.92%) but only the preference of slightly less than half of family members (47.79%). People with I/DD had the home of a family member or friend as their second preference (10.27%) and supervised home or apartment as their preference (4.86%). Family members of people with I/DD had supervised group home or apartment as their second preference (22.12%) and home of a family member or friend as their third preference (13.27%).

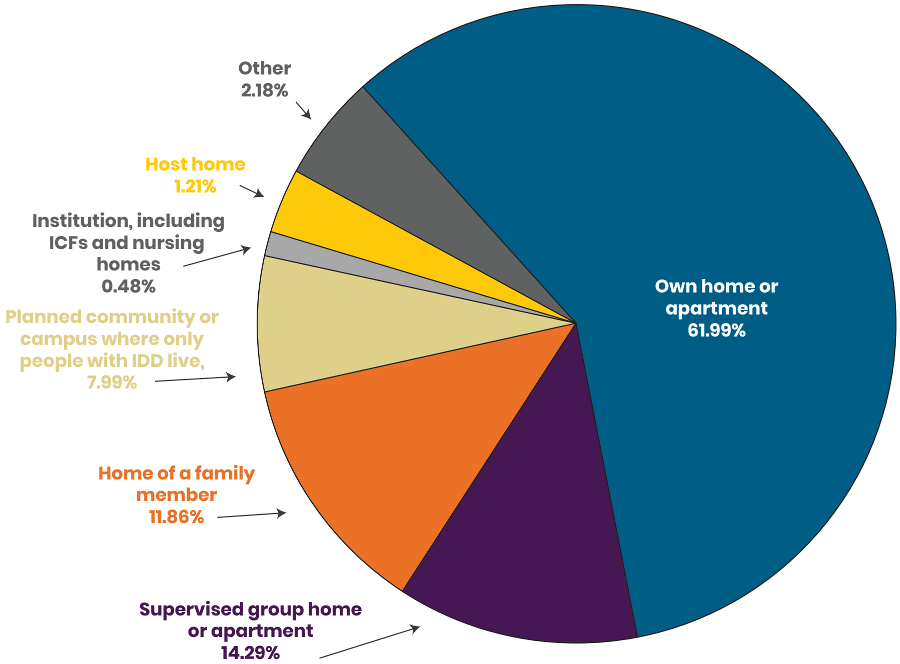

FIGURE 8. Dream Homes (all participants, all settings; n = 413).

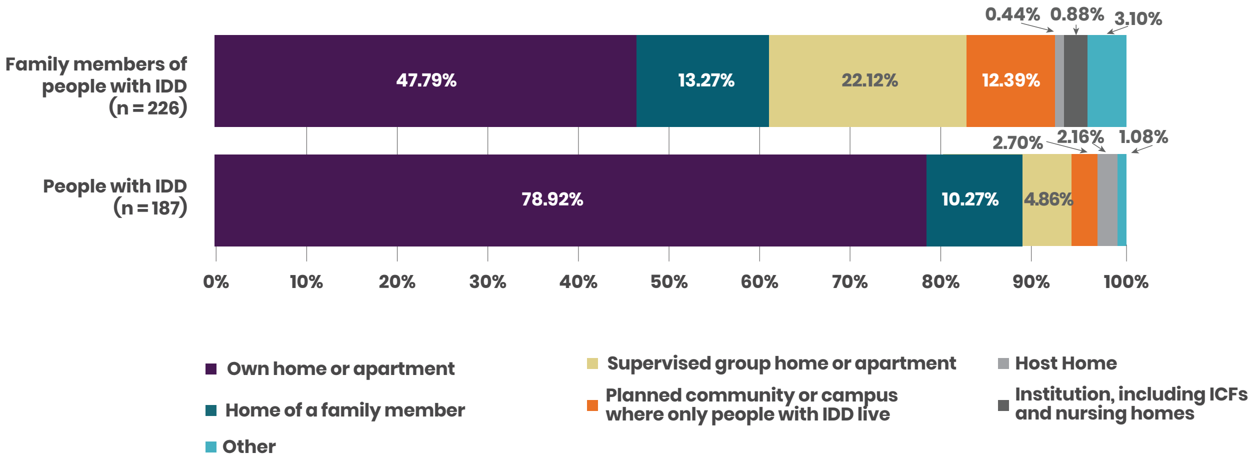

FIGURE 9. Dream Homes by Participant Group.

People with I/DD who currently lived in their own home or apartment were most likely to say they were already living in their dream home (*Table 9a*). Meanwhile, family members of people with I/DD who currently lived in a planned community or campus where only people with I/DD live were most likely to say this was their dream home for their family member with I/DD compared to other settings. Of those people who did not currently reside in their dream homes, both family members and people with I/DD reported their dream home was their own home or apartment, followed by home of a family member or friend.

Dreams also differed further when we compared both group and setting (*Table 9b*). For example, people with I/DD who lived in group homes were significantly more likely to say their dream home was with their family than family members of people in group homes (26.32% versus 8.22%). Family members of people with I/DD who currently lived in a planned community or campus where only people with I/DD live were also significantly more likely to say a planned community or campus was their dream home for their family member (95.45% for family members, 16.67% for people with I/DD), whereas people with I/DD who currently lived in a planned community or campus dreamt of living in their own homes or apartments (66.67% for people with I/DD, 4.55% for family members).

WHAT NEEDS TO CHANGE

When asked what needs to change about the current housing opportunities for people with I/DD, participants described policy and system changes, funding, system navigation and resources, staff and quality, person-centered choices, and philosophies of institutional and community living.

Policy and System Changes

In terms of policy and system changes, participants presented a variety of different recommendations. In general, they believed there should be more flexibility in government systems and programs. For example, one recommendation was to allow more waivers to pay for supports in people's own homes. Participants also recommended drawing attention to long waiver waiting lists. One participant also believed it should be easier to change states without risking losing services or having to start over on a waiting list.

> *"The number of persons on waiting lists is really deplorable"*
>
> — Family member of person with I/DD

Participants believed there should be programs to make it easier for people with disabilities to own their own homes. For example, one participant recommended special subsidies to assist people who have poor or no credit to obtain housing. Another participant recommended raising the asset limit so it would be easier for people to own their own home without having to sacrifice career opportunities (people need limited assets to qualify for services). Another mentioned that a related issue that needs to be changed is the marriage penalty – people should be able to legally marry without risking their services or benefits.

Others believed it should be easier for family members to buy houses for their family member with I/DD. These people described that many people are forced to buy houses for their family member with I/DD because of a lack of options; however, at the same time, they feel the federal government penalizes them for doing so because buying a house for this purpose is considered a non-business transaction and can hinder their Social Security benefits.

One participant believed more emphasis and resources should be put into Microboards and cooperatives. The participant commented, "The Microboard model is very successful in Canada and Australia… creating supports around an individual in their communities, and leveraging local resources and relationships of family members, neighbors, and friends."

Finally, it was also recommended that self-advocates with I/DD should not only be involved in any policy or system changes but should also be paid to help lead the policy and systems changes.

Funding

In addition to these structural changes, many participants emphasized a need to change funding structures and streams. People believed more money is needed to support people with disabilities, including funding so that people can afford homes that provide opportunities for independence and privacy.

> “ *Why do health and human services always bear the brunt of budget reduction? The health of a state, a country, may be measured in part by how its most vulnerable are cared for* ”
>
> — Family member of person with I/DD

Participants also recommended having better financial incentives for live-in companions/supports and having the option of paying family caregivers. In addition, participants spoke of the need to compensate direct support professional staff more. One participant also recommended there be funding for innovative housing ideas to help propel community living further.

> *I would pay staff enough to make those that love the field to be able to make it a career. Too often they sadly move on because of money*
>
> — Family member of person with I/DD

System Navigation and Resources

In terms of system navigation, participants believed the housing process needed to be simplified, with fewer hoops to jump through. The current process was described as being too complicated, making it very stressful, especially if a person with I/DD does not have support to help explain the process or to help advocate with them.

Participants described finding information and resources about different housing options as extremely difficult – as a maze of information. They recommended a national website that includes not only information and resources about how to navigate social security and government assistance related to housing but also that catalogs the different housing options available to people with I/DD. A number of participants also recommended that websites about housing be accessible for people with I/DD. One participant also recommended that there should be a transition specialist to help people navigate the housing system.

In addition, participants believed there needs to be more streamlining and simplifying to make it easier for people to navigate the system. Moreover, they also suggested more accountability and transparency, particularly in relation to agencies and success of placements.

Staff and Quality

Participants also believed that better overall quality of options was needed across housing types. This included, but was not limited to, safety, more living space, and access to transportation. This also included addressing structural issues, such as the fact that the majority of people with disabilities live in poverty, which makes finding quality housing extremely difficult. A need for increased quality and structural change is especially pertinent for people who need accessible housing, which participants described as almost impossible to find. Moreover, one participant noted that often settings are not truly accessible but rather just barely meet the Americans with Disabilities Act (ADA) compliance requirements.

A number of participants described that quality also entails ridding systems and settings of custodial models and institutional culture in community-based settings. One participant commented, "agencies feel like they and their staff are in charge of everything. They are not providing services that are client [person with

I/DD] and family driven." Another family member noted, "the government says it wants the licensed homes to be a family-like environment and people should have independence, freedom, and privacy. If so, then why do they require homes to have sign in/out logs, visitor logs, fire escape plans on walls, menus posted on walls, toileting charts, etc. This is not done at my house!!" Others noted that group homes should be less restrictive; for example, people should be able to move around more freely. Many participants believed services and supports should also be individualized, offer more choices, and be more flexible to better align with people's goals. Others thought there needed to be more housing options which "allow for more independence while still supporting the needs of the individual." Similarly, a few participants cautioned that some people were being over-supported.

Participants also recognized a crucial component of quality is direct support staff. There was a recognition that human service agencies often do not pay people enough to have reliable staff who stick around. In addition to receiving higher wages, people believed staff needed to be more qualified. Staff should be invested in "making sure that people with disabilities receive respect, [supports], and quality of life." It was also believed that people should be able to hire their own support staff.

Person-Centered Choices

Many participants emphasized the importance of choice; housing should "always allow for choice." Participants believed that people with I/DD should have the same range of housing options available to them that people without disabilities have. As such, there needs to be expanded options for integrated housing.

> “*Currently we end up with too much isolation and neglect because there aren't communities/neighborhoods/subdivisions developed with our needs in mind*”
>
> — Person with I/DD

Participants believed better choices should be available, with more availability of options, including more group homes. They noted that currently people are priced out of certain options and that there is a lack of affordable, accessible, and integrated housing. In addition to being able to choose what type of setting they want, people also believed they should be able to choose their housemates and roommates. One participant described that most people currently do not have a choice of where to live, who to live with, or who their residential support staff are. Another commented that it was very difficult to change homes if people change their minds.

A number of participants also drew attention to the ability of people with I/DD to choose where they live, rather than people choosing on their behalf. For example, participants said, “People with disabilities should have more input in any discussion that pertains to them,” and “give us the same opportunities as everyone else.” However, who should have input and get to make decisions was sometimes a point of contention between people with I/DD and family members of people with I/DD. For example, one person with I/DD commented, “I don’t want my parents to have the right to put me in an ICF or ‘intentional community.’” Meanwhile, one family member commented, “Not all people with disabilities understand that the decisions they make is not in their best interest. I feel that at times like someone else should make the decisions for them.” However, not all family members of people with I/DD had the same views when it came to who should be able to choose where people live – the beliefs were mixed. For example, one family member said, “I would like to see more protection for those who have guardians that do not always have the best information or care about that person’s best interest. I think the public appointed guardians are not always the best for people and some families are led to believe it’s the only option for those that they themselves cannot care for.”

> *Choice is empowering*
>
> — Person with I/DD

Philosophies of Institutional and Community Living

Another point of contention across survey participants was around the philosophies of institutional and community living. Although it should be noted that not all people whose family members with I/DD lived in institutional or segregated settings (n = 34) advocated for these settings – some mentioned wanting community options that offered adequate supports for their family member with I/DD – there was a small but vocal group of parents, all of which had family members with I/DD that lived in campus settings, who believed people should be able to choose segregated and institutional settings. These parents believed “options should be expanded not restricted.” For example, one parent said, “Choice, Choice, Choice. Too many so-called advocates and government regulators want to limit choice and reduce options. They want to impose what they think is the best living option rather than letting the individuals and families choose the option that best meets their needs and preferences.” In addition to emphasizing the need for choice, those in favor of segregated settings expressed that they believed these settings offer more opportunities, less isolation, and more supports, particularly to people with higher support needs. Although it was a very small group – only a handful of people – there were some family members who also blamed the lack of institutional options for people with higher support needs on “people who believe they know what’s best,” “influencers who think everyone belongs in one type of setting,” and “autism self-advocates [that] have ruined it for the severely autistic.”

Conversely, many other participants emphasized the need to expand community living and community integration. Some described that state-run institutions should be closed, while others believed the system should move away from congregate housing altogether because they believed “it’s moving us back to the days of institutional-level housing” and “it is immoral and disgusting, making people be like cattle on a ranch.” Still others spoke of the problematic assumption that “people with disabilities need to earn the right to live in the community.” Another participant also noted they believed that people with I/DD in institutional settings should have the opportunity to receive those services in the community instead of having to live in an institution. Furthermore, one participant pointed out, “the current lack of affordable, accessible, integrated housing is keeping people institutionalized.” Another participant suggested, “I think we need to get more creative about how we provide services to people with disabilities so there ARE more choices in living options that aren’t institutions, but community settings.”

RESULTS: NOMINAL GROUP TECHNIQUE (PART II)

Results: Nominal Group Technique (Part II)

The second part of the study involved a series of NGT sessions with people with I/DD and family members of people with I/DD. In total, 111 people with I/DD and family members participated in the NGT sessions. Findings are presented in terms of major and minor themes.

SYSTEM NAVIGATION

Why People Move

There were a number of factors that impacted why people moved across settings and/or from their original family home. Some people with I/DD moved because they experienced abuse or neglect either while living with family members or at a different residential setting. Other participants described moving as a result of emergency placements. For example, some people with I/DD noted they moved after a family emergency, such as their parents dying. A few other people with I/DD and family members described people moving as a result of medical or mental health needs. In some of these instances where people had to move because of health needs, some people were forced into different settings by their doctors, social services, or others. Meanwhile, other people with I/DD moved to a new home because they required more supports than their current home or provider could provide. Similarly, a few people had to move because of failed placements – the previous provider could not adequately support them.

Many other people with I/DD moved because their family members could no longer support them, often as a result of age, injury, or acquiring disabilities themselves. Family members described the emotional and physical toll caretaking can take on the caregivers. Family members also noted the need for respite and crisis services as well as the need for family support groups to help alleviate the pressures associated with supporting their family member with I/DD. A number of people with I/DD also specifically expressed not wanting to be a “burden” on their parents or their siblings who would be charged with supporting them if the parents were no longer able to do so. Meanwhile, a few other people with I/DD described moving because of fights or disagreements with family members.

Others described long waiting lists that impacted if, and when, they could move to a new setting. People with I/DD and family members described waiting years, if not decades, to be moved off a waiting list for services. Many noted that they or their family member with I/DD were only able to move off a waiting list because of an urgent situation, such as abuse, neglect, or family emergencies. For example, one participant with I/DD revealed after being on the waiting list for years, they finally moved her off when her mother was diagnosed with breast cancer and she became considered an emergency case as a result.

Often, people’s choices were shaped by the wealth and privilege of their families. The cost of some settings limited people’s options. Moreover, some people recognized that not everyone is fortunate enough to be able to have one parent be able to stay home from work or go down to part-time in order to serve as a caregiver. Those who were able to afford it stated they considered the possible solution of parents buying a home for their adult child with I/DD and then either donating it to an agency or having it staffed. Moreover, family members from a private institutional campus setting noted their ability to "pull out checkbooks" and "pool financial resources" whenever their provider had a need or wanted to develop new programs; one father described, "we're able to help compensate financially when there's a need. Whereas, with a [public group home], I don't know. I've never really had to worry about it, but I can imagine that would be a real frightening idea." Some participants also noted the financial burden the residential system can take on the family. For example, one mother described having little money to retire off of because of utilizing Social Security for her daughter, which she and her husband felt guilty doing in the first place. Others noted that while a local private campus setting had a good reputation, it required not only a sizable annual financial commitment but also for families to volunteer time every year – not something every family has the ability to do.

For some people, culture was another factor that impacted decision-making. As participants acknowledged, in some cultures people stay with family and it would not be considered appropriate for them to live elsewhere. Latinx participants, in particular, emphasized family commitments; while many of the Latinx parents recognized a need to find alternative solutions for when they got older, the majority had already made plans with the siblings or extended family members of the person with I/DD to help ensure a seamless transition.

Future planning was a big topic of discussion amongst sessions with family members of people with I/DD, regardless of their culture. Family members described their anxieties regarding what would happen to their family member with I/DD once they died. Some family members noted these concerns being the reason they moved their loved one to residential services now – they would rather be around when they did so to help ease the transition. Other family members outlined specific plans about where their family member with I/DD would live after they died. Still other parents acknowledged not having specific plans and worrying about what would happen.

> "*The future is a big blank for me. I don't know what I'm gonna do*"
>
> — Person with I/DD

How People Find Information

In terms of how people with I/DD and their families found information about what housing options were available to them, many participants described a confusing system where it was extremely hard to find information. Not only did people have to navigate a patchwork of resources and information and an excess of paperwork, they also described having to jump through hoops, particularly in a rigid service system.

In terms of the process they used to find information about their options, many participants described exhaustive online searches and research. Many others felt fortunate to find out information via word of mouth and networking with others, such as through disability or family groups. A few family members even described being thankful for having a mentor, often another parent who had experienced the same challenges and who walked them through the system. Some parents found information about the available options through their support coordinator or case worker, while others found out options from providers themselves. A few participants who had housing vouchers also described how the voucher shaped their eligibility and noted that sometimes they were provided with a list of available options. A handful of participants also commented that it was particularly difficult for them to find information because of a language barrier – information about different options and navigating the residential system was typically not available in their native language.

Once people with I/DD and family members did research about their potential options, many stated that they toured potential settings and completed site visits to compare different settings or homes. A few participants also described doing trial runs to determine if the setting was a possible option for their family member with I/DD. Many family members also described needing to advocate and/or educate people in order to get what they wanted.

Who Makes Decisions About Where People Live

In terms of who ultimately made the decision regarding where the person with I/DD would live, a few people with I/DD and family members explained that they either had no choice, selected the only setting that would take the person with I/DD, or were only able to choose between a few options, which was not truly a choice. For those that had choices between home options, only a small number of people with I/DD decided where to live. The majority of the time, family members decided where the person with I/DD would live. Most of the time people with I/DD were not even consulted in these decisions. Some people with I/DD did not question their family members' decisions, while others expressed wanting to be able to choose where they lived; still others questioned whether they are even allowed to pick where they live.

> “*Would it be possible if you could pick your own group home? The reason I'm asking because there's this one group home I want to move into because I got some friends in there and my girlfriend lives there, too. I want to live with them because I might be more comfortable with them*”
>
> — Person with I/DD

In terms of if, and how, family members made decisions on behalf of the person with I/DD, sometimes families, sometimes families made these decisions when their family member with I/DD was a young child and therefore the person with I/DD did not have an opportunity to contribute to the decision. Other times, family members made decisions on their behalf about what they believed was the best option. However, there was a small but vocal group of parents that were insistent that people with I/DD should not be able to make these decisions. They not only believed that “we know as parents what is best for them and what fits for them,” but also believed that people with I/DD could not be trusted with decisions, including about where they lived. For example, one of the parents who felt this way commented, “Why in the world would I say to her [adult daughter], ‘Where do you want to live?’ You know? I think a lot of parents think that their [adult] kids should be making those decisions. It’s scary.” Conversely, there were other people with I/DD and family members that described how families included the person with I/DD in conversations and that their preferences were considered and/or honored when families made the decision. Some family members described supporting their family member with I/DD to make the choice or considered which setting the person liked more. Other family members noted the need to balance honoring the voice of the person with I/DD with the support the person needs.

Other Structural Issues that Impact Decision-Making

In addition to the above factors which impact the decision-making of people with I/DD and their families, participants also discussed a number of systems and structural issues that played a role in whether they were able to choose where they lived and what choices they had available to them. A number of family members spoke to the lack of community infrastructure and how that made it very difficult for their loved ones with I/DD, particularly those people with higher support needs, to receive the support they needed in the community. Of those people whose family members with I/DD had failed community placements and had to move to more institutional settings, it was in large part a result of the inadequate services and supports they received in the community. Other family members spoke to the isolation that people with I/DD often face, even when in the community, because of a lack of adequate community infrastructure. For example, one parent described that as a result of a rigid system and a lack of staff, their adult son was not able to leave the house when he lived in a group home.

Many participants described poor reimbursement rates and a lack of overall funding as one of the largest issues in the residential service system. They recognized that agencies are often not funded enough to adequately support people with I/DD, especially those with high support needs or complex needs, and to provide person-centered services. Others noted the need to increase direct support staff wages, as staff turnover significantly impacts the stability and continuity of services for people with I/DD. A number of people also pointed to the long waiting lists for community-based services as indicative of the lack of adequate funding. Others suggested the funding structures needed to be more flexible, particularly in order to fund more supported living so people can live with their families.

As a result of systemic issues, such as a lack of community infrastructure and a funding crisis, a number of family members seriously contemplated uprooting their family and moving out of the state to receive services for their family member with I/DD. However, other family members recognized that moving across states also presents challenges, as when doing so as you have to start over with services and are placed at the bottom of the waiting list for services.

Those in rural communities also described a patchwork system which not only had less funding but also a lack of overall choice. Compared to urban and suburban communities, rural settings were noted for having a lack of choice in providers, a lack of services, and a lack of opportunities and activities for people with I/DD. However, a few people in rural settings described that the benefit of living in a rural community was that it was not only a close-knit community that was more likely to know the person with I/DD but that it was also easier for the person with I/DD to navigate independently because of its smaller size.

QUALITY: WHAT PEOPLE LOOK FOR, AND WHAT THEY DO AND DO NOT LIKE

Another theme of the NGT sessions centered around quality. People's ideas about quality not only revealed what factors impacted people's decision-making when deciding where to live and what is important to them but also their satisfaction regarding their current living situation. According to participants, there are many aspects to quality, including: features of the setting and neighborhood; a setting that has opportunities and activities; person-centered practices; relationships and opportunities for socialization; housemate and roommate issues; house rules; quality of support, providers, and staff; and ideology regarding community, independence, and ability.

Features of the Setting and Neighborhood

Foundational aspects of quality – necessities for any setting – included safety, security, and freedom from abuse and neglect. Both people with I/DD and family members stressed the importance of safety, not only in the home but also in the neighborhood and community. This also included people's basic needs being met, and, according to family members in particular, adequate medical care. Physical accessibility was also considered a foundational aspect of quality; however, many people described a lack of accessible housing options, particularly a lack of accessible group homes. Moreover, others also recognized that their current setting is still not completely accessible. For example, people with I/DD described not being fully able to reach items in their closet because of using a wheelchair or having to climb a lot of stairs which are problematic for their knees. A few people also described the need for the larger community to be accessible so people with physical disabilities can navigate stores, restaurants, sidewalks, and so on.

> “*If I had a dream home, I would want it to be accessible so I could be able to do the stuff on my own and be able to reach everything, or be able to get to everything, that I needed to get to*”
>
> — Person with I/DD

In addition, many people described the importance of a setting being quiet and having privacy. People described the importance of alone time and having a physical space people could go to when they needed to be alone. Many people also wished people with I/DD did not have to share bathrooms and added that their own bathroom would add to their sense of privacy. Likewise, people often wished for more space in general in terms of the physical size of the rooms and homes of people with I/DD. People also wished for a smaller number of people residing in the homes.

People also described wanting and liking having a nice home that was in good condition and felt like a home. A home's basic amenities were also important. For example, a large number of people with I/DD described the importance of laundry – they wanted to be able to do it on their own and do so in their own homes rather than having to go somewhere. People with I/DD also commented that sometimes there were problems with their washers and dryers, and they needed to have machines that were fully functional and have enough machines so more people could do laundry. Amenities such as a backyard or garden area where people with I/DD could spend time outside were important to some people. Others stressed the importance of television, Internet, and other technology.

Pets were also a big topic of conversation, especially for people with I/DD. Those few people that were allowed to have pets described the ability to do so as very important to them. Those people with I/DD who were not allowed to have pets or certain pets wanted to be able to have cats and dogs in their homes. While some participants with I/DD recognized that some people are allergic to pets, they noted they were not sure if they would be allowed to have pets in their home, even if no one was allergic.
In terms of features of the wider neighborhood, friendly neighbors as well as the availability, variety, and closeness of businesses, shops, places of worship, and recreation were important to participants. Transportation was also considered an important aspect of where people lived. People described a lack of public transportation options, transportation that is difficult to navigate or inconvenient, and a shortage of vehicles for their house.

Opportunities, Activities, and Things to Do

One of the most important aspects regarding where people lived was having opportunities, activities, and things to do. The ability to get out of the house and go into the community and run errands, go shopping, go out to eat, or participate in social or recreational activities was paramount to both people with I/DD and family members. Some people described having limited options to choose from every week, while others had more control over what they do and where they go. Employment opportunities and/or day service opportunities were also described as vital.

> “*Work gives them a sense of purpose, makes life meaningful*”
>
> — Family member of person with I/DD

Despite the want and need to participate in community activities, a number of people described people with I/DD as often having to sit around the house and having nothing to do, particularly on weekends. For example, some people described that they or their family member with I/DD spend a lot of time isolated and sitting around or watching television, including having to watch television shows that the staff want to watch. Some family members invoked the idea of 'warehousing' to describe the lack of opportunities people have. For many people, when they did get to leave the house, their house typically did so as a group. As a result, they could not do certain things if their housemate or roommate did not want to or if their housemate/roommate misbehaved. It was also recognized that support staff can be critical in order to facilitate opportunities and activities; not only do staff often provide transportation, a lack of staff motivation can also serve as a barrier to community inclusion.

A related issue which limited people's opportunities was a lack of access to their own money. Sometimes, people with I/DD were only allowed to go places if they had money to spend. Moreover, staff often controlled the access people with I/DD had to money and when, or where, they were able to access their own money. For example, one person with I/DD noted that when the supervisor who carries the money was not at work or was at another location, they cannot access their own money. Many participants also noted the limited spending money people receive each month to spend, which limits not only what they can do but also their involvement in the community – it is not person-centered.

Person-Centered Practices

Both the requirement that people go out as groups and a lack of meaningful activities and opportunities do not reflect services and supports that are person-centered. Many participants described the lack of individualization and person-centered services and supports available to people with I/DD. While some participants described the positive impact of person-centered planning models, others pointed out that people's goals were often not person-centered, realistic, or meaningful. A few participants also noted that while person-centered planning was great in theory, without funding associated with it, it has little impact.

Relationships and Opportunities for Socialization

Another feature that people with I/DD and family members of people with I/DD looked for and valued was the ability to have and maintain social opportunities and relationships. There was a concern about people with I/DD being isolated and lonely. As such, people wanted people with I/DD to have the ability to create and maintain friendships, romantic relationships, and other forms of relationships (*e.g.*, community and natural supports). People with I/DD wanted to be able to see their friends and/or romantic partners more often. Some people with I/DD wanted to be able to have their friends and/or romantic partners over to their house more often, while others wished

> *My daughter was 20 and they wanted 40 year olds or 50 year olds with her*
>
> — Family member of person with I/DD

they could live near or with their friends or romantic partners. Many participants, both people with I/DD and family members of people with I/DD, added that they also wanted to see their family members more as well as live closer to them. While proximity to family was an important part of where people lived, often there were other factors that outweighed proximity, such as availability, opportunities, and quality of support. While many people wanted to be close to their families, a number of family members of people with I/DD described being willing to drive further to the setting if it was the right fit.

Housemate and Roommate Issues

Housemates and roommates significantly impacted people's satisfaction with where they or their family member with I/DD lived. When people got along with their housemates and roommates, had things in common with them, and had similar habits, it positively impacted their views of the setting. However, conflict with housemates and roommates quickly soured people's view of their home and significantly increased their desire to move to another setting.

Abuse and Conflict amongst Housemates and Roommates

People with I/DD, in particular, described homes that were rife with conflict and violence; not only were arguments and yelling constant, injuries from housemates and roommates were commonplace. People with I/DD described incidents where they were pushed, scratched, punched, stabbed, sexually assaulted, and abused by their roommates or housemates. A few participants also mentioned incidents where housemates stole from them or tried to take advantage of them. While sometimes these incidents prompted organizations to move roommates/housemates, other times people with I/DD were forced to continue to live with the people who injured them or caused arguments.

As a result of these conflicts, as well as the benefits to living with friends and similar people, many people wanted the ability to choose their own housemates and roommates. A few also mentioned they felt more comfortable living in a home where everyone was the same gender as themselves.

House Rules

People with I/DD also spent a significant amount of time in NGT sessions discussing house rules of congregate settings – the ways their lives at home are regulated and restricted on a daily basis. Rules ranged from smaller and less important ones to larger rights violations.

There were many rules about what people could and could not do in their own home. Some people were not allowed to sleep in, while others were not allowed to fall asleep or take a nap in their living room. Some people were not allowed to stay up late or had a specific bedtime. For example, one woman who had a physical disability described being physically put to bed while her friends were still over, and she had no control

> “*I just feel like there's too many rules and there's many things that I can't do*”
>
> — Person with I/DD

over the situation. Others described having to shower at certain times, especially to accommodate staff schedules.

There were also rules about if and when people could leave the house and/or have friends over. Many people disclosed rules limiting whether they were allowed to leave the house at all or noted that they needed to be home at a certain time. A few people also revealed that their staff even lock their front door so they cannot leave the house. Others expressed frustration that there were only certain times that they could have friends visit or sleep over, and/or that they needed to get approval before anyone could come over. Some people experienced rules regarding phone 'privileges' – when they could call their friends or family and who they were allowed to call. A group of siblings with I/DD who participated in the research together also disclosed that they were told they should not spend so much time together and that their staff told them they cannot hug their family members who live with them. A few people also experienced special rules regarding romantic relationships.

People with I/DD were especially frustrated about rules regarding food. There were often rules about if people could cook their own food at all or make themselves a snack. A number of people were required to wear gloves every time they were in the kitchen, regardless of if they were helping to prepare a meal for the house or if they were simply making themselves a sandwich. While some people liked that their staff cooked on their behalf, others wanted the opportunity to cook for themselves and/or their house as well as the ability to choose what they were eating. While some people had opportunities to cook, others were allowed to cook only on certain days or were not allowed to cook anything at all. Sometimes, rules also extended to what people were allowed to eat, sometimes for dietary reasons but other times because of house procedures. For example, a few people described that their agency policy was that they were not allowed to drink alcohol despite being older than 21 and their parents permitting it. Some people described that their house rule was that they were not allowed to eat anything without staff being home. Others were not allowed to bring anything into their bedroom, even water. Other people exclaimed that they were not even allowed to go into the kitchen in their home.

A number of people with I/DD also brought up agency rules regarding medication administration. While most of the time staff were the ones administering medication, many people with I/DD expressed interest in wanting to learn more about their medication and to administer the medications themselves. To many people with I/DD, the ability to take their own medications was important to them, and it was one of the rules they most wanted to change.

While a few people with I/DD believed these rules were for their own good – to "protect" them – others implicitly recognized the injustice, specifically calling out that rules were different at their current residential home and their parent's home or across different providers. For example, one person with I/DD pointed out that at her parent's home she can shower whenever she wants without supervision, whereas at her residential home she is restricted to only showering when staff are available. Another example is one person who pointed out that at their parent's home they are allowed to take their own medication, but at their residential home, the agency will not let them do so.

Quality of Support, Providers, and Staff

Support

Another factor that impacted where people lived was the quality of support the residential setting offered. Both people with I/DD and family members described the need for support services, both for activities of daily living, such as bathing, health, and safety, and for skills related to independent living, such as grocery shopping and paying bills. When speaking to the quality of support, some family members mentioned the stability of the residential setting, such as the ability for their loved one to age in place while receiving services tailored to the person's current level of need.

Some family members specifically looked for the availability of 24/7 around-the-clock support for their loved one with I/DD. Yet, a number of people described difficulty in finding residential options that adequately supported people with multiple disabilities, people with complex medical or mental health/behavioral needs, and people with higher support needs. Not only were there a dearth of options for people with higher support needs, participants felt that the quality of the available options was significantly lacking. Many people described having to change settings, often to more institutional settings from community-based ones, as a result of inadequate services and support systems for medically complex people or people with I/DD and mental health disabilities. For example, one father described ultimately having to place his son who is Deaf and has I/DD and mental health disabilities in a state-operated developmental center after three failed community placements. He explained that settings for Deaf people often did not know how to support people with I/DD and 'behavioral challenges,' whereas settings for people with I/DD often lacked people who could communicate with his son via sign language. This father, as well as many other people, recognized that staff are not adequately trained to support people with complex needs.

Conversely to those who struggled to receive adequate and quality supports, some people with I/DD and family members described people with I/DD being over-supported. As a result of a rigid and not person-centered service system, these people described receiving around-the-clock supports but not actually needing them.

Providers

The quality of support people received depended significantly on the organizations and staff that provided those services. Family members of people with I/DD commented that they sought providers that not only shared their philosophies but also those that they trusted and those that would have open communication with them.

People also described avoiding poor-quality providers that not only failed to provide adequate support but also whose home settings were dirty and bordered on neglect. Others described fearing retaliation by providers when complaining about issues or abuse. While a few people reported fearing retaliation from staff when lodging complaints – having to ‘pick their battles’ – others described the larger implications of reporting to the state, worrying that the state might shut down a setting that they depended on. In fact, it was not uncommon for people to describe providers closing, either due to issues with the state, or more frequently, because of financial collapse. The result of these closings was often a lack of stability in the lives of people with I/DD as their provider closed, merged, or was purchased by another provider.

Staff

It was also not uncommon for people with I/DD to experience a lack of continuity in their services and supports, largely due to support staff turnover. Very often the quality and availability of support staff radically transformed not only people’s satisfaction with a setting but also their quality of life. In many ways, staff can serve as either facilitators of, or gatekeepers to, quality residential services. When they had good staff, people with I/DD and family members were appreciative of the support and care they received. The best staff were those that were not only the right fit but also those who cared. People also recognized that quality staff led to opportunities as good staff gave people with I/DD choices and facilitated community activities. When people had good staff, their staff were often the thing they liked most about their residential setting. However, the majority of people also described issues with staff, including turnover, a lack of training, and staff who did not do what they were supposed to. Staff turnover, and the resulting staff shortages, were recognized as a barrier to quality. Not only did the lack of consistency and availability of staff impact the stability of the lives of people with I/DD, it also made it more difficult for people with I/DD to receive person-centered services since new staff were less likely to know them. Participants recognized that the turnover issues largely stem from a lack of funding and inadequate wages. Moreover, people described issues with staff who were not adequately trained to support people, including people with I/DD with complex needs.

People with I/DD also described a number of issues with staff not doing what they are supposed to or participating in problematic behavior. For example, a number of people with I/DD said that their staff yell at them and make them cry. Others noted a lack of respect from staff, which ranged from staff playing favorites to staff not treating people with dignity. Some people noted staff do not listen to them when they express their wants or needs; a few people admitted that they became so frustrated when staff did not listen, that it would lead them to ‘act out.’ While communication was a general issue, there were a handful of people that expressed that they did not like when staff spoke about them in front of them, including those staff that spoke another language in front of them. A number of people also explained that their staff often sleep during the day or spend time on their phones despite not being allowed to do so.

> “*It’s true, you get what you pay for, and if you wanna get the quality people and if you want the people to stay there and have fulfilling careers, then you gotta pay ‘em*”
>
> — Family member of person with I/DD

Community Participation Versus Belonging to a Community

Community was another factor that was important to people regarding where people with I/DD lived. However, community was most often discussed in relation to a place people with I/DD visited or had allocated time for, rather than a place people with I/DD belonged and/or integrated into. While only a few people described having true community access and inclusion, the majority of participants favored increased community integration. In fact, people with I/DD cherished time in the community, with it often being one of their favorite things about where they lived. However, how people described the community was indicative of the limited access people have to community inclusion and integration. The overwhelming majority of people with I/DD and family members described people having 'community time' – the designated time they individually or as a group get to go 'into' the community for a few hours. Often these were group outings to eat at a restaurant, such as McDonalds, or go to a store, such as Walmart or Target. Sometimes people with I/DD were able to choose where 'community time' was spent, while other times they were not able to choose and herded as a group. Some people with I/DD also described 'personal shopping days' where they were individually brought to purchase personal hygiene items or get a haircut. A few others were allowed to have alone time in the community, but it was generally still a specific and scheduled amount of time, such as a few hours. Still others reporting not having 'earned' their community access yet and therefore not being allowed to have community time or walk around their neighborhood.

> “*I don't have community access yet for the houses, so I haven't walked or nothin' but they're gonna let me have community access soon*”
>
> — Person with I/DD

In/Dependence and Ability

Similarly, independence was another concept that was considered to be something people had to 'earn' or 'prove.' Not only did some family members speak of their loved with I/DD only in the context of dependence and inability, some people with I/DD also internalized these messages about dependence and ability and spoke specifically about how they were or were not 'capable' of doing things.

Despite the framing of people with I/DD in relation to dependence and ability, the overwhelming majority of people with I/DD wanted to be more independent. Both people with I/DD and family members wanted people with I/DD to have more opportunities to participate in 'independent living skills,' such as cooking, budgeting, laundry, and cleaning. Sometimes, these were skills that people did not receive the opportunity to learn. For example, many people wanted to learn how to cook their own meals. Other times, people with I/DD had skills but were prevented from doing things independently because of organizational policies and house rules. For example, some people wanted to be able to clean their home, but the rule was that staff did so. People with I/DD and family members both recognized that participating in these tasks helped people with I/DD grow, develop new skills, and become more independent; a number of people with I/DD also believed they needed to achieve a certain level of competence before they could live on their own like they wanted to, or even just before they would be allowed to do what they wanted to do at their current residential setting.

FUTURE HOMES AND WANTED CHOICES

As far as where people wanted to live in the future, the majority of people with I/DD expressed wanting to live on their own. Both people with I/DD and family members wished people with I/DD could live closer to their family members, and some also wanted people with I/DD to be able to live with their family members. Other people with I/DD wanted to live with their romantic partner or friends. A couple of family members expressed that they wanted their loved ones with I/DD to live in an intentional community where they themselves could also live. Other family members did not hope for a specific setting type per say, as long as it was a setting that allowed people with I/DD to live up to their full potential and have a meaningful life.

In addition to the setting type, people also wanted to have the option of choosing between having their own room and having a roommate. Moreover, people wanted the ability to choose their housemates as well as to choose smaller setting sizes. A number also said they would like to choose having their own bathroom as well. In essence, people wanted a range of different options to choose from.

DISAGREEMENTS BETWEEN PEOPLE WITH I/DD AND THEIR FAMILIES

Overall, family members of people with I/DD were the ones who decided where the person with I/DD would live. While some family members consulted their loved one regarding where they would live, the majority of the time their adult child with I/DD was not given a choice. When there were disagreements between people with I/DD and their family members regarding where people should live, most often the preferences of the person with I/DD were overridden by the family members' preference. Sometimes, the lack of choice given to the person with I/DD was described as a consequence of the family member serving as the person's guardian. While some people with I/DD were frustrated by the lack of choices and input they had as a result of their guardian and wished to be their own guardian, there was also a small but vocal group of parents who believed people with I/DD should not be allowed to be their own guardian and should not be allowed to make their own choices because the person with I/DD is not "capable" of making decisions and the guardian "knows what's best."

However, our study did reveal different wants and preferences across people with I/DD and family members of people with I/DD. Families generally thought the current setting their loved one with I/DD lived in was the best option. More often than not, it was because this setting was the one that they selected in the first place. In contrast, although people with I/DD were generally satisfied with their current setting, the overwhelming majority dreamt of living in their own home or apartment. In addition, while the themes from the NGT sessions with people with I/DD and family members of people with I/DD were overall consistent, family members tended to focus more attention on health and safety. Although people with I/DD believed health and safety were important, they were more likely to emphasize opportunities, independence, and rights. In addition, people with I/DD were more likely to discuss factors that impacted their daily lives, such as rules, rights, and staff, whereas family members, having different experiences than people with I/DD, focused more on system-wide challenges, such as housing taxes, regulations, and policy.

RANKING OF PRIORITIES

At all NGT sessions, people were asked to vote on what they believed the top priorities should be and/or what is most important to them regarding where people with I/DD live, based on the content they shared. Votes were tallied and aggregated across the different sessions and the participant groups.

The following were the top 10 priorities across all NGT participants:

1. Want to live independently (on their own)
2. Quality support staff
3. Opportunities to go into the community
3. Person-centered services and supports
5. Activities and programs
5. Want to live close to family members
7. Safety and security
8. Support staff turnover and short staffed
9. Want independence, freedom, and no restrictions
10. Don’t like food rules

The following were the top 10 priorities of people with I/DD:

1. Want to live independently (on their own)
2. Opportunities to go into the community
3. Activities and programs
4. Don’t like food rules
4. Want independence, freedom, and no restrictions
6. Quality support staff
6. Want to live close to family members
8. Want to make decision regarding where to live with family member/guardian (as opposed to family deciding on their behalf)
9. Lack of available transportation
10. Want to have friends/romantic partner visit and/or sleep over

The following were the top 10 priorities of family members of people with I/DD:

1. Person-centered services and supports
2. Support staff turnover and short staffed

3. Services are dependent on funding; there needs to be more funding
4. Quality of provider agency
5. Safety and security
6. Staff treat people like individuals
7. Need appropriate/quality supports
8. System is failing people, especially people with complex support needs
9. Want socialization opportunities
10. Staff lack training

DISCUSSION & RECOMMENDATIONS

Discussion and Recommendations

SUMMARY OF FINDINGS

The aim of this study was to explore factors that impact the decision-making of people with I/DD and their families as they think about and plan for leaving their family home. To do so, this mixed methods study included a national online survey as well as in-person NGT sessions in Illinois.

Although there were many reasons people with I/DD moved from their family homes or moved across residential settings, most commonly they moved as a result of a need for more support, family members having difficulty taking care of them, independence, or emergency placements as a result of health or safety concerns. People with I/DD and family members of people with I/DD completed rigorous research in order to determine which options were available to them when looking for a new home. Despite exhaustive online searches, many people noted that resources and information are extremely difficult to find, particularly as there was no central place to seek resources.

Once armed with as much information as they could find, people still found themselves with limited options. Those people with I/DD with higher support needs as well as those with I/DD and mental health disabilities, in particular, found very few community-based housing options and were sometimes forced to turn to institutional settings instead. While people with I/DD and family members often experienced limited housing options to choose from, the overwhelming majority of the time, family members made the decision regarding where people with I/DD would live. While sometimes people with I/DD were consulted in the decision regarding where they would live, most of the time they were not consulted, although they wished they were.

While most people with I/DD (and family members) reported being satisfied with their current home, there were a number of factors that increased or decreased satisfaction with where people with I/DD lived. Safety, security, freedom from crime, and freedom from abuse and neglect were considered foundational components of quality settings. People also wanted and liked settings that offered independence, and opportunities to access the community for activities like shopping, going to restaurants, running errands. People also wanted meaningful things to do during the day, including employment opportunities. The quality of services and supports, including the quality of providers and quality and sustainability of staff, also played an important role in people's satisfaction and what they looked for in a setting. In addition, there were differences in what people with I/DD and family members of people with I/DD felt was most important. People with I/DD tended to focus on cost and location so they could participate in the life of the community and have things to do. Meanwhile, family members tended to focus on safety, and proximity to family.

The ability to have options to choose from is important to people with I/DD and their families. However, when asked what choices people had if they were to decide to move from their current setting to a new one, many people continued to have (or perceived they had) limited options available to them. For example, people with I/DD and family members frequently reported they did not believe they would be able to select a new room or a new roommate or housemate. In fact, only slightly more than half of participants even believed they would be able to select a new housing type.

When participants were asked about what their dream home for themselves/their family member with I/DD would be like in a system with unlimited potential and resources, the overwhelming majority of people's dreams were very small. It was not common for people to say they wanted people with I/DD to live in a mansion or in some exotic location; rather, people dreamt of having independence and opportunities, a setting that was physically accessible, seeing their friends whenever they wanted, being treated with respect, and having well paid and qualified support staff. As far as the type of setting, most people with I/DD and family members wanted people with I/DD to live in their own home. In fact, almost 90% of people with I/DD in our online survey wanted to live in their own home (79%) or a family home (10%), with very few dreaming of living in congregate settings.

IMPLICATIONS AND RECOMMENDATIONS

The findings from our study have wide implications and, as such, we have a number of recommendations for policy and practice. While all the themes represent opportunities for improvement, we highlight a number of key recommendations based on our findings and the findings mirrored in existing research. These include system navigation and transparency, community infrastructure and quality, and facilitating opportunities and choice for people with I/DD.

System Navigation and Transparency

Participants in this study described a housing system where information was hard to find, there were multiple hoops to jump through, and one often needed the ability to advocate – a privilege in and of itself – in order to get adequate services. As such, one of our recommendations is the creation of a central clearinghouse for information and resources regarding housing and people with I/DD. Having one centralized location to provide information about the housing options available, and the choices and rights people are entitled to, would greatly benefit people with I/DD and their family members as they navigate the housing system and weigh the benefits and disadvantages of certain settings related to what they are looking for. While we recognize that systems and services vary from state to state, this clearinghouse could serve as a starting point to help people become familiar with the system. It could also connect people with the proper people and channels to navigate housing options in their own state. Alternatively, states could create their own clearinghouses, which would be tailored to the options and regulations in their state.

In addition to having a central place for information and resources, the entire process of finding residential funding streams, available providers, and/or housing options, and transitioning between settings would benefit from streamlining. While case managers are often designed to fit these roles, a lack of case manager training and knowledge, case manager turnover, and a lack of uniformity across case managers significantly reduce their effectiveness.

Community Infrastructure and Quality

Research indicates there are more positive outcomes associated with community integration, compared to institutional settings (Beadle-Brown et al., 2016; Hemp et al., 2014; Lakin et al., 2011; Larson et al., 2013; Larson & Lakin, 1989; Mansell & Beadle-Brown, 2004). Compared to institutional settings, people with I/DD in the community have increased self-determination, larger social networks, increased participation in community life, and increased choice (Beadle-Brown et al., 2016; Larson et al., 2013).

People opposed to deinstitutionalization often argue people with I/DD need more care than the community can provide or that institutions result in higher quality (Bagenstos, 2012). However, research has found people with higher support needs benefit from deinstitutionalization and community residential supports and have better outcomes in the community (Lakin et al., 2011; Mirenda, 2014; Young, 2006). In fact, "research denies support for the assertion that people obtain greater or even equal benefit in adaptive behavior from living in institutions… this research suggests that those benefits very consistently accrue more to the people who leave institutions to live in small community homes" (Larson & Lakin, 1989, p. 30).

Yet, we recognize, based on the current community infrastructure, that not only are there limited settings that can support people with higher support needs in the community, many people with I/DD who live in the community still struggle to be meaningfully included in, and engaged with, the community (Cullen et al., 1995; Forrester-Jones et al., 2002; Friedman, 2019b; Ligas Consent Decree Monitor, 2016, 2017; Spagnuolo, 2016). For example, a number of participants in our study pointed out that the lack of adequate, accessible, and integrated housing options resulted in people being institutionalized. In addition, not only were many people with I/DD in our study lonely, community was also described as a place one 'went to' or had 'time in' – not as true community integration or inclusion. Community is not just a place one physically goes to, but "a place people have a stake in, a place people feel they belong" (Hingsburger, 2017). As such, there are a number of factors regarding the community infrastructure that need to be addressed.

Expanding and Restructuring Funding

To remedy the inadequate community infrastructure, increased funding is necessary. While we recognize many states are operating in limited fiscal landscapes, many of the issues people with I/DD and family members discussed in this study stem from funding structures and systems. It should be recognized that funding is an investment in quality – it directly impacts the quality of services and supports as well as quality of life for people with I/DD. Moreover, as community-based settings are also significantly more cost-effective than institutions (Braddock et al., 2017), if states continue and/or expand their deinstitutionalization efforts, they can utilize the financial surplus to expand community-based funding as well as reduce large waiting lists.

In addition to increasing funding, we believe it is also necessary to restructure funding so that it is easier for people with I/DD to receive supports and services in their own homes, in family homes, and in shared living arrangements – outside of traditional congregate settings, – as these were the most preferred settings in our study. In addition, research suggests people with I/DD living in their own homes or family homes have some of the highest quality of life outcomes in a wide range of areas, regardless of the complexity of supports needed (Friedman, 2019b).

In addition, given the stress and financial burden family caregivers face and the fact that the majority of people with I/DD in the United States live with and are supported by unpaid family caregivers (Braddock et al., 2015; Rizzolo, Hemp, Braddock, & Schindler, 2009), more resources should be allocated or redirected towards supporting family caregivers. For example, one small change that would not result in increased expenditures is expanding who can provide paid personal care services to include family members.

Attending to Direct Support Professional Workforce Issues

An adequate housing service system and community infrastructure is also highly dependent on a well-paid and well-trained direct support professional workforce. There is an astronomically high annual direct support professional turnover rate (approximately 30-70% on average), which is largely due to inadequate wages, a lack of benefits, a taxing workload, and a lack of training and career ladder (American Network of Community Options and Resources, 2017; Bogenschutz, Hewitt, Nord, & Hepperlen, 2014; Keesler, 2016; Micke, 2015; Wolf-Branigin, Wolf-Branigin, & Israel, 2007). Turnover significantly hinders the quality of life and community integration of people with I/DD (Britton Laws, Kolomer, & Gallagher, 2014; Friedman, 2018a; Robbins, Dilla, Sedlezky, & Johnson Sirek, 2013; Smergut, 2007; Venema, Otten, & Vlaskamp, 2015). For example, as described in this study, staff often served as gatekeeper to, or facilitators of, community integration and civil rights. As such, people with I/DD will not have quality residential services and supports until the workforce crisis is resolved. In addition to increasing reimbursement rates for support staff wages, one suggested mechanism for decreasing direct support professional turnover is the professionalization of direct support staff. The anticipated benefits of standardized credentialing of support staff include enhanced quality supports as a result of having competency-based training and expanded tenure of direct support professionals as a result of a career ladder and wage stabilization (Smith, Macbeth, & Bailey, 2019).

Increasing Community-Based Supports for People with Higher Support Needs and Mental Health Disabilities

A number of people in our study detailed inadequate community-based services and residential options for people with higher support needs and people with I/DD and mental health disabilities. In fact, inadequate services are one of the primary causes of people with higher support needs and people with I/DD and mental health disabilities being re/institutionalized (Charlot & Beasley, 2013; Hall et al., 2005; Lulinski, 2014; Mansell, 2006; McIntyre, Blacher, & Baker, 2002). This issue is particularly pertinent because people with I/DD are three to five times more likely to have a mental health disability than the general population (Allott, Francey, & Velligan, 2013). Residential providers must be intentional about facilitating the quality of life outcomes of people with higher support needs and people with I/DD and mental health disabilities. Moreover, as residential providers are often limited by the funding they receive, more funding is needed in order to facilitate services and supports for people with higher support needs and people with I/DD and mental health disabilities.

Implementing Person-Centered Services and Supports

Findings from this study also revealed a service system that is far from person-centered. For example, not only were many people with I/DD only brought into the community on group outings, but they also faced a lack of choices, both in terms of what settings were available to them as well as in their daily lives. The choices, options, and the quality of the supports that people with I/DD received were often dependent on their family's wealth, the community in which they lived, and their privilege in terms of their access, ability to advocate and/or have family members advocate on their behalf, and the existence of information and resources available in their language and consistent with their culture.

In addition, participants from both Part I and Part II noted that choices and opportunities for people with I/DD were significantly impacted by custodial models of care. Spagnuolo (2016), argues, "the legacy of institutionalization and congregate care has shaped current residential services, meaning that 'services today have become standardized, inflexible and unaccountable to those they serve'" (n.p.). The hallmarks of custodial models of care include: a lack of choice, not listening to people with I/DD, rights restrictions, a culture of care rather than support, an underfunded system, a lack of true community integration, inflexibility, and a lack of community-based options for people with higher support needs – all of which were found in our study. For example, a number of participants described people with I/DD being 'managed' rather than supported. Many other people with I/DD mentioned rights violations, a lack of true community integration, and a lack of choices in their lives. It is necessary to uproot custodial and institutional ideology within both policy and practice. While doing so will not be easy, it is necessary to reduce ableist attitudes and rights violations, increase people's choices and opportunities, and facilitate the quality of residential services.

Provider organizations must move beyond custodial models of care and compliance by not only reexamining their norms and assumptions but also by introducing evidence-based person-centered practices and being accountable to the people with I/DD they support. While person-centered practices can help expand the quality of services and supports, currently they often tend to be abstract theory rather than actual practices. True person-centered practices pay attention to individualized personal outcomes and supports – they are not group activities, warehousing, or a lack of choice. Instead, organizational supports should support people to have a meaningful life *as defined by that person* – people should be supported to "live a good life through experience, decision-making, and balanced risk" (Friedman, In press-b, p. 19).

While these large changes require uprooting custodial culture, it is important to recognize that if provider organizations are unstable because of an underfunded system, that is not going to be a good starting point for advancing change. An unstable provider system does not align with innovation. In addition, the current rigidity of the funding structure is not conducive for person-centered individualized services and supports. It is also important to recognize that for people with I/DD, residential services are often packaged with other LTSS – it is all connected and tied to other services and supports. For example, for many people with I/DD in this study, where people lived and the provider organization for that setting impacted their day or employment opportunities and their access to the community. While the aim of this study was to examine where people lived, we would be remiss if we did not highlight that the lives of people with I/DD are directly affected by where they live not only in terms of location but also in terms of setting. Where they live impacts what they do during the day, in terms of day/employment opportunities, as well as transportation, access to the community, and access to services. For these reasons, as well as others described above, it is necessary to re-examine funding mechanisms to see if there are any opportunities for improvement.

Honoring People's Rights and Stopping Rights Violations

Related to custodial models of care, our study also revealed that the rights of people with I/DD are routinely violated and their lives restricted, sometimes on a daily basis. For example, people were told they could not have visitors, could not enter their own kitchen, could not bring water into their own room, could not fall asleep on their sofa, could not hug their sibling, and many other restrictions. While house rules and restrictions were often implemented under the guise of protecting people, they "can come at the expense of independence, self-determination, privacy, due process, and other quality of life areas" (Dunbar, 2019, n.p.). Not only do these rules limit what people can do in their own homes, they can also serve to establish power hierarchies. "Sometimes, staff members may knowingly or unknowingly establish a rule that people receiving services feel they have no choice but to follow... Often times, these 'unwritten' rules develop as a result of the perceived conveniences that they provide staff, and tend to remain in place due to a lack of understanding about what a restriction really means. Rules can also take the form of hierarchical dynamics, where staff expect that people receiving services ask for permission to have a snack, use a phone or computer, etc." (Dunbar, 2019, n.p.).

Unfortunately, due to rules and regimentation being so central to the lives of people with I/DD lives as well as the fact that people with I/DD are often taught to comply, many of the people with I/DD in this study simply accepted house rules and rights violations as unfair but simply a part of their lives – restricting the rights of people with I/DD has become normalized. Instead, we need to honor the rights and autonomy of people with I/DD. Historically, instead of being given civil rights, people with I/DD have been given 'protections' and exclusions in order to 'protect' them and society (Carey, 2003). The Supreme Court in *Olmstead* determined that people with disabilities have the right to receive services in the most integrated setting appropriate to their needs. People with I/DD should receive supports in the most integrated settings possible and have the same opportunities to access the community as people without disabilities. However, progress toward implementing the integration mandate of the ADA and *Olmstead* has been slow and uneven.

In recognition that people with disabilities often lack community integration and person-centered services and supports, the Medicaid HCBS Settings Rule identifies the specific qualities of a “community-based” setting and requires states to provide *meaningful* community opportunities for people with I/DD receiving Medicaid HCBS. In addition, the HCBS Settings Rule aims to uphold a number of rights which people in this study were lacking. For example, in addition to community access, people must be able to choose from a range of settings, including non-disability specific ones, and must have the ability to choose a private unit and/or choose their roommates (Centers for Medicare and Medicaid Services, 2014, n.d.). Moreover, it upholds individual rights by emphasizing that people must have keys to their homes, must be able to have visitors at any time, must be able to choose their services, and many more of the rights related to autonomy, independence, and choice (Centers for Medicare and Medicaid Services, n.d.) that most of the people in this study were denied. While our findings indicate a clear need for the implementation of the HCBS Settings Rule, it also suggests the HCBS Settings Rule has the potential to radically transform the LTSS service system and the lives of people with I/DD. However, because progress to implement these requirements has been slow, states have until 2022 to come into full compliance with the Rule, and because of funding limitations, much more work is necessary to ensure the HCBS Settings Rule is implemented with fidelity.

Ultimately, upholding the rights of people with I/DD comes down to respect. Research suggests that people with disabilities that are respected are less likely to experience rights limitations; not only that, but those people who are respected are more likely to receive appropriate due process when rights limitations are imposed (Friedman, 2018b). “Elements of respectful practice include: recognizing a person’s personhood; supporting the person to control their life; recognizing complexity regarding choice, judgments, wellbeing, and dignity; and, sensitivity as reflected through interactions and language (Bigby, Frawley, & Phillips, 2014)” (Friedman, 2018b, n.p.).

Facilitating Opportunities and Choice-Making for People with I/DD

In addition, there are also additional ideological and cultural changes which must occur to maximize the housing decision-making opportunities of people with I/DD and family members of people with I/DD.

Informed Choice

People with I/DD have often been conditioned to comply (Finlay & Lyons, 2001; Finlay & Lyons, 2002; Townsend-White, Pham, & Vassos, 2012) and accept what they have – “‘if this is all you’ve ever had, you might think it’s good enough’” (Friedman, In press-b, p. 17). We believe this – the tendency for acquiescence – is likely one of the reasons many of the people with I/DD in our study said they were generally satisfied with where they lived, but once the question was reframed and they were asked about their dream home, they wanted to change where they lived. Choices that are not informed as well as choices between only two options, are not truly choices. “As experiences inform perspectives on quality, people must also have the opportunities to try new things. Moreover, for services to be considered quality, people with I/DD need a wide array of options and innovations to choose from… Informed choice involves the three E’s —

education, experience and exposure. It's important to ask, 'do people with disabilities have the same education, exposure, and experience as people who are not receiving supports?'" (Friedman, In press-b, p. 17)

Increasing Choice and Decision-Making

Our findings also revealed significant differences between the wants and needs of people with I/DD and family members of people with I/DD. People with I/DD taking part in this study often wanted to live by themselves more often than family members wanted them to. Although people with I/DD believed health and safety were important, people with I/DD tended to emphasize the importance of rights, opportunities, and independence. Family members, on the other hand, tended to focus on health and safety significantly more often. These discrepancies between what people with I/DD and family members want raise concerns, as family members commonly decided where their loved one with I/DD should live, often without the person with I/DD being offered the opportunity to, at the very least, contribute to the decision.

While family members typically have the best interests of their loved one with I/DD in mind, family members have different relationships to, and with, disability than people with I/DD – they have an arm's length experience, whereas people with I/DD have lived experience. Even those constantly interacting with people with I/DD do not have firsthand knowledge about I/DD and are not aware of all the things that impact the daily lives of people with I/DD (Carlson, 2010; OToole, 2013). People with I/DD in this study not only reported being less satisfied with where they lived than family members of people with I/DD, they also were more likely to emphasize factors that impacted their daily lives, such as house rules or interactions with staff. We recognize that family members of people with I/DD have valuable opinions and experience to share; however, people with I/DD must be included in decisions that impact their lives.

The fact that people with I/DD were often not consulted about a decision that would radically transform their lives is also problematic because family members may often also internalize ableist ideas (Neely-Barnes, Graff, Roberts, Hall, & Hankins, 2010). A recent study of 180,000 family members of people with I/DD found that while the majority of family members of people with disabilities did not consciously have negative attitudes about disability, unconsciously (implicitly) – without them realizing – they held negative attitudes towards people with disabilities (Friedman, 2019a); this finding is similar to other research about trends of ableism (*e.g.*, Abberley, 1987; Barnes, 1997; Baynton, 2001; Campbell, Gilmore, & Cuskelly, 2003; Harpur, 2011; Harris & Fiske, 2007; Keller & Galgay, 2010; Kumari-Campbell, 2009; Linton, 1998; Makas, 1988; Neely-Barnes et al., 2010; Shakespeare, 1996; Stern, Dumont, Mullennix, & Winters, 2007).

While it was only a small number of family members in our study, a few made problematic and ableist comments about disability. For example, there were comments such as "inclusion isn't meant for everybody," comments from family members blaming self-advocates for limiting access to institutions, and comments expressing the belief that people with I/DD should not be able to choose where they lived. These disagreements around priorities, as well as peoples' attitudes towards disability, play a role in the extent to which people with I/DD have choices about where they live, as well as the choices that are made with them, or on their behalf. It is critical to recognize the voices and lived experience of people with I/DD alongside and in contrast to family members.

Dignity of Risk, Ability, and Independence

In addition to working to reduce ableism more broadly, one mechanism to help promote the choice and decision-making opportunities of people with I/DD is by attending to dignity of risk. Avoidance of risk is often built into the physical and social environments of people with I/DD (Perske, 1972). However, "it is difficult to learn how to make decisions and handle risk if the chance to undertake either of these activities is denied. It is particularly important for people with [I/DD], who will usually need more practice than others to master skills, but these experiences tend to be denied by parents anxious to minimize risk" (Hudson, 2003, p. 261).

Yet, self-advocates "are saying they are willing to take risks like anyone else to live like other adults around them. They want places to turn to for support, but they also want the feeling of respect and self-confidence that comes from taking chances" (Shapiro, 1994, p. 192). While there may be concerns that people are not capable of independent decision-making, the best support involves balancing duty of care and dignity of risk – supporting the person to become informed, and to understand the benefits and risks, rather than take away their choices altogether. Family members may have concerns about the decision-making abilities of people with I/DD; however, it is important to note common conceptualizations of disability, including those from this study, focus on what people with disabilities cannot do and places in society they cannot participate (Carey, 2003; Keller & Galgay, 2010; Spagnuolo, 2016). This tendency was mirrored in this study by an emphasis on the dependency and inability of people with I/DD to do things. Disability is often still seen as synonymous with "personal pathology, of individual difficulties and of dependency in the face of care" (Goodley, 1997, p. 369). Conceptions of people with I/DD as incapable, incompetent, or low ability are not only widely exaggerated, they also result in paternalism, which limits people's opportunities and choices (Barnes & Mercer, 2003; Harris & Fiske, 2007; Reid, Stoughton, & Smith, 2006; Spassiani & Friedman, 2014; Susman, 1994). Deficit-based understandings of people with disabilities not only locate the problem within the individual, they also produce an understanding that there is something wrong with the person that must be managed, rather than reinforce that flexible person-centered supports are needed to best support people with I/DD to maximize their strengths to achieve their goals. "Challenging the social construction of impairment, embodied in resistance to the label, is central to the lives [of self-advocates] and their movement" (Caldwell, 2011, p. 322); as such, we need to have higher expectations for people with I/DD.

Independence was considered something that people with I/DD must 'earn' or 'prove' to a certain threshold before they were given choices, opportunities, and even rights. In this way, we hold people with I/DD to a higher standard – people without disabilities do not have to prove or earn independence, instead they often learn through trial and error. While we recognize people with I/DD may need more support and education about certain skills to increase independence, the people in our study wanted these opportunities. They wanted to learn how to cook, clean, budget, and do their laundry. While congregate settings often devote time to increasing people's 'independent living skills,' it is not always done in a meaningful way. As aforementioned, people with I/DD faced a large number of rules that not only limited what they could do but also required them to participate in tasks not of their choosing. Moreover, we would suggest there should be an emphasis on these skills much earlier, pre-transition from high school, so there does not have to be a delay in transitioning to the least restrictive environment.

While we recognize that people with higher support needs in particular may have increased challenges, and people may have concerns about the abilities of people with more higher support needs, Wehmeyer and Bolding (2001) remind us, "the prevalent assumption is that these individuals [with I/DD and higher support needs] cannot or do not become self-determined, an opinion formed *almost exclusively* on assumptions about individual capacity or the limitations thereof… However, by *addressing issues* pertaining to environment and opportunity, and by providing adequate supports and accommodations, people with [I/DD] can enhance their self-determination and assume greater control of their lives" (emphasis original; p. 374). In addition, people with I/DD and higher support needs are "demonstrating that they [can] learn content [and achieve things] never imagined possible 30 years ago" (Spooner & Browder, 2015, p. 30). While not everyone may want, need, or be able to make their own decisions, people with I/DD should be supported to be involved in decisions that impact their lives, in whatever means possible and relevant to that person. In alignment with interdependence – "[a] cultural value of supporting one another" – having support or assistance does not mean people with I/DD are not self-determined (Caldwell, 2011, p. 320; Nonnemacher & Bambara, 2011; Spassiani & Friedman, 2014).

Self-Determination

In addition to the importance of people with I/DD contributing to decisions about their lives, choice and dignity of risk can also facilitate self-determination and empowerment and honor the values of self-advocacy (Chappell, 2000; Kietzman & Benjamin, 2016; Spassiani & Friedman, 2014). According to self-advocates, "by helping each other take charge of our lives and fight discrimination, [self-advocacy] teaches us how to make decisions and choices that affect our lives so we can be more independent" (Hayden & Nelis, 2002, p. 221). Self-advocates also note, "making choices and decisions for ourselves is an important part of who we are. It is fundamental to having control over our own lives and important for securing all other rights: if we are not allowed to make our own decisions, how can we have a voice in anything else that is important to us?" (Inclusion International, 2014, n.p.)

According to The Arc (2018) position statement on self-determination: "people with I/DD have the same right to self-determination as all people and are entitled to the freedom, authority, and supports to exercise control over their lives. People with I/DD must understand that they can direct and influence circumstances that are important to them. This right to self-determination exists regardless of guardianship status. Family members, friends, and other allies play a critical role in promoting self- determination by providing supports and working collaboratively to achieve the individual's goals. Families, friends, and other allies should understand, recognize, and promote the rights and responsibilities of self-determination and respect the limitations on their own authority. Service providers, educators, and substitute decision-makers must recognize and respect the individual's right to self-determination and the limitations on their authority. To this end, people with I/DD must be able to lead in decision-making and problem-solving about all aspects of their lives and have the supports they want to make decisions; advocate for themselves with the assurance that their desires, interests, and preferences will be respected and honored; and… take risks to achieve the lives they desire" (n.p.).

LIMITATIONS

When interpreting the results of this study, a number of limitations should be noted. It should be noted that people volunteered to participate in both the online survey and the NGT, and there is a possibility of self-selection bias as a result. For example, the majority of our sample was White, and the family member participants in particular were also overwhelmingly women. However, it is important to note that we had an acceptable confidence interval (3.95) for the online survey and the qualitative NGT analysis met saturation; moreover, our findings mirror that of past research (see reference list). Although we welcomed people with higher support needs to receive help to complete the online survey, it is important to recognize that surveys may not be accessible to all people. It is important to note that we minimized the number of people and family members who represented family homes as the aim of this study was to examine settings other than family homes. Finally, we would like to remind readers that the NGT was conducted in one state – Illinois. However, the findings from the NGT in Illinois mirror the findings from the national survey so not only serve as a form of triangulation of the data but also reinforce national trends.

CONCLUSION

The aims of this study were to increase knowledge of housing decision-making and identify barriers to housing decision-making for people with I/DD. Findings from both an online national survey and in-depth NGT sessions with people with I/DD and family members of people with I/DD revealed that due to the systemic denial of the rights of people with I/DD, the lack of choices available to them, the lack of stability people experience, and the lack of funding available, radical systems and cultural changes are necessary. People with I/DD are not only held to a higher standard regarding independence and house rules but are also often told to accept problematic conditions in their daily lives, such as isolation, lack of choices, and violence from housemates. In addition, while person-centered practices are wonderful, they are more often than not theories, not actual practice.

People with I/DD cherish what little time they have in, and with, the community and want more opportunities to integrate into their communities. People with I/DD want to contribute to the choices that impact their lives, such as where they live, who they live with, and how they spend their time. People with I/DD want opportunities to learn new skills, participate in tasks such as cleaning, cooking, and medication administration, and interact with friends and romantic partners. In essence, people with I/DD want full lives and for people to treat them with respect. We need to listen to people with I/DD as the experts about their own lives, including their wants and needs, and work to restructure the system accordingly. While more people with I/DD are living in the community than ever before, more work is necessary to have an adequate community infrastructure that *ensures* all people with I/DD have choices, options, and opportunities.

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TABLES

TABLE 1

Demographics of Online Survey Sample (n = 615)

	Across sample (*n* = 615)		People with I/DD (*n* = 308)		Family members (*n* = 307)	
Category	*N*	*%*	*n*	*%*	*n*	*%*
Participant group						
Person with I/DD	287	46.67%	287	93.18%		
Person with I/DD and family member of person with I/DD	21	3.41%	21	6.82%		
Family member of person with I/DD - parent	208	33.82%			208	67.75%
Family member of person with I/DD - partner/spouse	7	1.14%			7	2.28%
Family member of person with I/DD - sibling	61	9.92%			61	19.87%
Family member of person with I/DD - other	31	5.04%			31	10.10%
Setting of person/family member with I/DD (*n* = 610)						
Own home or apartment	309	50.66%	197	64.59%	112	36.72%
Supervised group home or apartment	157	25.74%	61	20.00%	96	31.48%
Home of a family member	62	10.16%	13	4.26%	49	16.07%
Planned community or campus where only people with I/DD live	30	4.92%	6	1.97%	24	7.87%
Institution, including ICFs and nursing homes	14	2.30%	4	1.31%	10	3.28%
Home of a friend	13	2.13%	9	2.95%	4	1.31%
School dormitory	8	1.31%	3	0.98%	5	1.64%
Host home	5	0.82%	5	1.64%	0	0.00%
Homeless	2	0.33%	2	0.66%	0	0.00%
Other	10	1.64%	5	1.64%	5	1.64%
Disability of person/family member with I/DD*						0.00%
Intellectual disability	367	59.67%	186	60.39%	181	58.96%
Autism spectrum disorder	212	34.47%	91	29.55%	121	39.41%
Cerebral palsy	102	16.59%	53	17.21%	49	15.96%
Down syndrome	52	8.46%	12	3.90%	40	13.03%
Epilepsy or seizure disorders	27	4.39%	10	3.25%	17	5.54%
Fetal alcohol spectrum disorder	17	2.76%	10	3.25%	7	2.28%
ADD or ADHD	17	2.76%	10	3.25%	7	2.28%
Visual impairment	12	1.95%	1	0.32%	11	3.58%
Bipolar disorder	12	1.95%	3	0.97%	9	2.93%
Anxiety	11	1.79%	3	0.97%	8	2.61%
Other psychiatric disability (not listed)	10	1.63%	5	1.62%	5	1.62%
Learning disability	9	1.46%	8	2.60%	1	0.33%
Physical disabilities	8	1.30%	4	1.30%	4	1.30%
OCD	7	1.14%	1	0.32%	6	1.95%
Brain injury	6	0.98%	5	1.62%	1	0.33%
Spina Bifida	6	0.98%	4	1.30%	2	0.65%
Depression	6	0.98%	3	0.97%	3	0.98%
Schizoaffective disorder	6	0.98%	1	0.32%	5	1.63%

Hearing impairment	5	0.81%	0	0.00%	5	1.63%
PTSD	5	0.81%	5	1.62%	0	0.00%
Speech impairment or communication disorder	4	0.65%	2	0.65%	2	0.65%
Prader-Willi syndrome	3	0.49%	1	0.32%	2	0.65%
Other	76	12.36%	33	10.71%	32	10.39%
Gender (*n* = 606)						
Woman	403	66.50%	162	52.94%	241	80.33%
Man	195	32.18%	138	45.10%	57	19.00%
Genderqueer	2	0.33%	1	0.33%	1	0.33%
Nonbinary	2	0.33%	2	0.65%	0	0.00%
Other	4	0.66%	3	0.98%	1	0.33%
Race*						
White	496	80.65%	239	77.60%	257	83.71%
Black	74	12.03%	46	14.94%	28	9.12%
Latinx	26	4.23%	13	4.22%	13	4.23%
Asian	10	1.63%	7	2.27%	3	0.98%
Indigenous	9	1.46%	6	1.95%	3	0.98%
Native Hawaiian or other Pacific Islander	2	0.33%	0	0.00%	2	0.65%
Other	13	2.11%	9	2.92%	4	1.30%
Age of participant (*n* = 561)						
18 to 24	30	5.35%	25	9.19%	5	1.73%
25 to 34	122	21.75%	100	36.76%	22	7.61%
35 to 44	97	17.29%	64	23.53%	33	11.42%
45 to 54	109	19.43%	50	18.38%	59	20.42%
55 to 64	122	21.75%	29	10.66%	93	32.18%
65 to 74	69	12.30%	3	1.10%	66	22.84%
75+	12	2.14%	1	0.37%	11	3.81%
Age of family member with I/DD* (if applicable; *n* = 297)						
Less than 18	21	7.07%			21	7.07%
18 to 24	54	18.18%			54	18.18%
25 to 34	117	39.39%			117	39.39%
35 to 44	53	17.85%			53	17.85%
45 to 54	35	11.78%			35	11.78%
55 to 64	23	7.74%			23	7.74%
65 to 74	6	2.02%			6	2.02%
75+	4	1.35%			4	1.35%
Family income (*n* = 592)						
Less than $20,000	232	39.19%	211	70.10%	21	7.22%
$20,000 to $34,999	64	10.81%	34	11.30%	30	10.31%
$35,000 to $49,999	57	9.63%	22	7.31%	35	12.03%
$50,000 to $74,999	101	17.06%	22	7.31%	79	27.15%
$75,000 to $99,999	46	7.77%	4	1.33%	42	14.43%
Over $100,000	92	15.54%	8	2.66%	84	28.87%
Highest level of education (*n* = 595)						
Less than high school diploma	65	10.92%	59	19.73%	6	2.03%

High school degree or equivalent	153	25.71%	133	44.48%	20	6.76%
Some college, no degree	91	15.29%	47	15.72%	44	14.86%
Associate degree	50	8.40%	21	7.02%	29	9.80%
Bachelor's degree	126	21.18%	23	7.69%	103	34.80%
Master's degree	82	13.78%	14	4.68%	68	22.97%
Professional degree (e.g., MD, DDS, DVM)	18	3.03%	2	0.67%	16	5.41%
Doctorate (e.g., PhD, EdD)	10	1.68%	0	0.00%	10	3.38%
Employment status (*n* = 607)						
Employed full time (40+ hours a week)	167	27.51%	25	8.17%	142	47.18%
Employed part time (39 hours or less a week)	142	23.39%	110	35.95%	32	10.63%
Retired	84	13.84%	12	3.92%	72	23.92%
Unable to work	81	13.34%	71	23.20%	10	3.32%
Unemployed and looking for work	43	7.08%	37	12.09%	6	1.99%
Unemployed and not looking for work	30	4.94%	27	8.82%	3	1.00%
Self-employed	25	4.12%	8	2.61%	17	5.65%
Homemaker	20	3.29%	3	0.98%	17	5.65%
Student	15	2.47%	13	4.25%	2	0.66%
Region (*n* = 603)						
Suburban	261	43.28%	117	38.36%	144	46.91%
Urban	201	33.33%	114	37.38%	87	28.34%
Rural	141	23.38%	74	24.26%	67	21.82%
Decision-making authority of person/family member with I/DD (*n* = 609)						
Makes own decisions without support	92	15.11%	84	27.45%	8	2.64%
Makes decisions with support from people they trust	296	48.60%	174	56.86%	122	40.26%
Power of attorney	20	3.28%	3	0.98%	17	5.61%
Guardian	198	32.51%	43	14.05%	155	51.16%
Other	3	0.49%	2	0.65%	1	0.33%
Primary communication method of person/family member with I/DD (*n* = 609)						
Verbal/spoken language	532	87.36%	289	94.14%	243	80.46%
Facial/body expression	52	8.54%	8	2.61%	44	14.57%
Communication device	18	2.96%	8	2.61%	10	3.31%
Sign language	7	1.15%	2	0.65%	5	1.66%
Person/family member with I/DD receives support to take care of themselves or their home (*n* = 611)						
Yes	469	76.76%	208	67.53%	261	86.14%
No	142	23.24%	100	32.47%	42	13.86%
Average daily support of person/family member with I/DD (*n* = 597)						
None	57	9.55%	40	13.56%	17	5.63%
On call - support only as needed	81	13.57%	49	16.61%	32	10.60%
0 to 3 hours/day	120	20.10%	71	24.07%	49	16.23%
4 to 6 hours/day	76	12.73%	41	13.90%	35	11.59%
7 to 12 hours/day	47	7.87%	21	7.12%	26	8.61%
13 to 23 hours/day	32	5.36%	13	4.41%	19	6.29%
24/7 – around-the-clock	180	30.15%	57	19.32%	123	40.73%
Other	4	0.67%	3	1.02%	1	0.33%
Person/family member with I/DD receives government funded services (*n* = 608)						
Yes	454	74.67%	212	69.28%	242	80.13%
No	100	16.45%	60	19.61%	40	13.25%
Unsure	54	8.88%	34	11.11%	20	6.62%

Note. * = Could fall into multiple categories

TABLE 2

Demographics of Nominal Group Technique Participants (n = 111)

	Across sample (*n* = 111)		People with I/DD (*n* = 69)		Family Members (*n* = 42)	
Category	*n*	%	*n*	%	*n*	%
Participant group						
Person with I/DD	69	62.16%	69	100.00%		
Family member of person with I/DD – parent	36	32.43%			36	85.71%
Family member of person with I/DD – sibling	3	2.70%			3	7.14%
Family member of person with I/DD – other	3	2.70%			3	7.14%
Setting of person/family member with I/DD*						
Own home or apartment	10	9.01%	6	8.70%	4	9.52%
Supervised group home or apartment	45	40.54%	39	56.52%	6	14.29%
Home of a family member	20	18.02%	5	7.25%	15	35.71%
Planned community or campus where only people with I/DD live	31	27.93%	16	23.19%	15	35.71%
Institution, including ICFs and nursing homes	5	4.50%	2	2.90%	3	7.14%
Other	2	1.80%	1	1.45%	1	2.38%
Disability of person/family member with I/DD* (n = 110)						
Intellectual disability	70	63.64%	49	72.06%	21	50.00%
Autism spectrum disorder	24	21.82%	8	11.76%	16	38.10%
Cerebral palsy	16	14.55%	8	11.76%	8	19.05%
Down syndrome	14	12.73%	7	10.29%	7	16.67%
Epilepsy or seizure disorders	9	8.18%	6	8.82%	3	7.14%
Bipolar disorder	3	2.73%	3	4.41%	0	0.00%
Anxiety	3	2.73%	2	2.94%	1	2.38%
ADD or ADHD	2	1.82%	2	2.94%	0	0.00%
Visual impairment	2	1.82%	1	1.47%	1	2.38%
OCD	2	1.82%	1	1.47%	1	2.38%
Hearing impairment	1	0.91%	1	1.47%	0	0.00%
Other	14	12.73%	3	4.41%	11	26.19%
Gender (*n* = 110)						
Woman	67	60.91%	39	57.35%	28	66.67%
Man	40	36.36%	28	41.18%	12	28.57%
Nonbinary	1	0.91%	0	0.00%	1	2.38%
Other	2	1.82%	1	1.47%	1	2.38%
Race* (*n* = 107)						
White	81	75.70%	48	73.85%	33	78.57%
Black	14	13.08%	11	16.92%	3	7.14%
Latinx	11	10.28%	5	7.69%	6	14.29%
Asian	1	0.93%	1	1.54%	0	0.00%
Native Hawaiian or other Pacific Islander	1	0.93%	1	1.54%	0	0.00%
Other	1	0.93%	1	1.54%	0	0.00%

Age of participant (n = 101)						
18 to 24	9	8.91%	8	12.90%	1	2.56%
25 to 34	14	13.86%	12	19.35%	2	5.13%
35 to 44	15	14.85%	14	22.58%	1	2.56%
45 to 54	14	13.86%	9	14.52%	5	12.82%
55 to 64	27	26.73%	13	20.97%	14	35.90%
65 to 74	16	15.84%	6	9.68%	10	25.64%
75 and older	6	5.94%	0	0.00%	6	15.38%
Age of family member with I/DD (if applicable) (n = 38)						
Below 18	1	2.63%			1	2.63%
18 to 24	7	18.42%			7	18.42%
25 to 34	17	44.74%			17	44.74%
35 to 44	7	18.42%			7	18.42%
45 to 54	5	13.16%			5	13.16%
55 to 64	1	2.63%			1	2.63%
Family income (*n* = 52)						
Less than $20,000	17	32.69%	16	76.19%	1	3.23%
$20,000 to $34,999	4	7.69%	1	4.76%	3	9.68%
$35,000 to $49,999	8	15.38%	4	19.05%	4	12.90%
$50,000 to $74,999	7	13.46%	0	0.00%	7	22.58%
$75,000 to $99,999	5	9.62%	0	0.00%	5	16.13%
Over $100,000	11	21.15%	0	0.00%	11	35.48%
Highest level of education (*n* = 109)						
Less than high school diploma	19	17.43%	17	25.37%	2	4.76%
High school degree or equivalent	48	44.04%	42	62.69%	6	14.29%
Some college, no degree	11	10.09%	6	8.96%	5	11.90%
Associate degree	6	5.50%	1	1.49%	5	11.90%
Bachelor's degree	13	11.93%	1	1.49%	12	28.57%
Master's degree	8	7.34%	0	0.00%	8	19.05%
Professional degree (e.g., MD, DDS, DVM)	3	2.75%	0	0.00%	3	7.14%
Doctorate (e.g., PhD, EdD)	1	0.92%	0	0.00%	1	2.38%
Employment status (*n* = 107)						
Employed full time (40+ hours a week)	5	4.67%	0	0.00%	5	11.90%
Employed part time (39 hours or less a week)	15	14.02%	7	10.77%	8	19.05%
Retired	32	29.91%	29	44.62%	3	7.14%
Unable to work	13	12.15%	11	16.92%	2	4.76%
Unemployed and looking for work	11	10.28%	11	16.92%	0	0.00%
Unemployed and not looking for work	3	2.80%	3	4.62%	0	0.00%
Self-employed	21	19.63%	2	3.08%	19	45.24%
Homemaker	6	5.61%	1	1.54%	5	11.90%
Student	1	0.93%	1	1.54%	0	0.00%
Region (*n* = 107)						
Suburban	55	51.40%	36	54.55%	19	46.34%
Urban	33	30.84%	21	31.82%	12	29.27%
Rural	19	17.76%	9	13.64%	10	24.39%

Decision-making authority of person/family member with I/DD (*n* = 109)						
Makes own decisions without support	13	11.93%	12	17.91%	1	2.38%
Makes decisions with support from people they trust	34	31.19%	22	32.84%	12	28.57%
Power of attorney	4	3.67%	3	4.48%	1	2.38%
Guardian	58	53.21%	30	44.78%	28	66.67%
Primary communication method of person/family member with I/DD (*n* = 109)						
Verbal/spoken language	94	86.24%	65	97.01%	29	69.05%
Facial/body expression	12	11.01%	1	1.49%	11	26.19%
Sign language	1	0.92%	0	0.00%	1	2.38%
Communication device	1	0.92%	1	1.49%	0	0.00%
Other	1	0.92%	0	0.00%	1	2.38%
Person/family member with I/DD receives support to take care of themselves or their home (*n* = 109)						
Yes	101	92.66%	2	2.99%	6	14.29%
No	8	7.34%	65	97.01%	36	85.71%
Average daily support of person/family member with I/DD (*n* = 102)						
On call - support only as needed	5	4.90%	3	4.55%	2	5.56%
0 to 3 hours/day	8	7.84%	5	7.58%	3	8.33%
4 to 6 hours/day	10	9.80%	5	7.58%	5	13.89%
7 to 12 hours/day	8	7.84%	4	6.06%	4	11.11%
13 to 23 hours/day	3	2.94%	1	1.52%	2	5.56%
24/7 – around-the-clock	68	66.67%	48	72.73%	20	55.56%
Person/family member with I/DD receives government funded services (*n* = 107)						
Yes	99	92.52%	3	4.48%	3	7.50%
No	6	5.61%	62	92.54%	37	92.50%
Unsure	2	1.87%	2	2.99%	0	0.00%

Note. * = Could fall into multiple categories (in the case of setting, two family members had multiple children with disabilities)

TABLE 3a

Did People Have Options When Looking for Their Current Setting?

		Participant Group % (*n*)		Current Setting % (*n*)								
Available options	Across participants % (*n*)	People with I/DD	Family members of people with I/DD	Own home or apartment	Supervised group home or apartment	Home of a family member	Planned community or campus where only people with I/DD live	Institution, including ICFs and nursing homes	Home of a friend	School dormitory	Host home	Other
No choice	1.78% (10)	2.11% (6)	1.44% (4)	1.43% (4)	3.27% (5)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)
Current setting was the only option	56.80% (315)	**60.99%** **(172)**	**52.38%** **(143)**	63.08% (176)	59.06% (88)	54.90% (28)	37.93% (11)	50.00% (6)	27.27% (28)	42.86% (3)	0.00% (0)	**0.00%** **(0)**
Had options	41.46% (230)	**36.89%** **(104)**	**46.18%** **(126)**	35.48% (100)	37.67% (56)	45.10% (23)	62.07% (18)	50.00% (6)	72.73% (75)	57.14% (4)	100.00% (5)	**100.00%** **(10)**

Note. Bold = statistically significant difference ($p < 0.05$ or less).

TABLE 3b

Available Housing Options When Looking for Current Home

		Participant Group % (*n*)	
Available options	Across participants % (*n*)	People with I/DD	Family members of people with I/DD
Own home or apartment	57.04% (320)	**65.85% (187)**	**58.59% (133)**
Supervised group home or apartment	39.57% (222)	**30.99% (88)**	**59.03% (134)**
Home of a family member or friend	25.49% (143)	**21.48% (61)**	**29.60% (82)**
Planned community or campus where only people with I/DD live	10.34% (58)	**7.75% (22)**	**13.00% (36)**
Institution	8.02% (45)	5.99% (17)	10.11% (28)
School dormitory	1.96% (11)	2.46% (7)	1.44% (4)
Host home	1.25% (7)	2.11% (6)	0.36% (1)
Other	4.10% (23)	2.11% (6)	6.14% (17)
No choice	1.78% (10)	2.11% (6)	1.44% (4)

Note. People could not select more than one setting. Bold = statistically signifigant difference (p < 0.05 or less)

TABLE 4

Choices Available to Participant When Selecting Current Setting

		Participant Group % (*n*)		Current Setting % (*n*)								
Choices	Across participants % (*n*)	People with I/DD	Family members of people with I/DD	Own home or apartment	Supervised group home or apartment	Home of a family member	Planned community or campus where only people with I/DD live	Institution, including ICFs and nursing homes	Home of a friend	School dormitory	Host home	Other
Chose where to live												
Yes	80.25% (447)	80.51% (219)	84.76% (228)	**89.38% (244)**	**71.63% (101)**	83.33% (45)	93.10% (27)	75.00% (9)	**40.00% (4)**	66.67% (4)	100.00% (5)	75.00% (6)
No	16.88% (94)	19.49% (53)	15.24% (41)	**10.62% (29)**	**28.37% (40)**	16.67% (9)	6.90% (2)	25.00% (3)	**60.00% (6)**	33.33% (2)	0.00% (0)	25.00% (2)
Choose with whom to live												
Yes	68.90% (381)	**77.17% (213)**	**62.92% (168)**	**89.13% (246)**	**40.71% (57)**	75.47% (40)	53.57% (15)	36.36% (4)	45.45% (5)	33.33% (2)	100.00% (5)	55.56% (5)
No	29.29% (162)	**22.83% (63)**	**37.08% (99)**	**10.87% (30)**	**59.29% (83)**	24.53% (13)	46.43% (13)	63.64% (7)	54.55% (6)	66.67% (4)	0.00% (0)	44.44% (0)
Choose neighborhood												
Yes	67.34% (369)	68.75% (187)	70.00% (182)	**79.64% (219)**	**58.45% (83)**	62.00% (31)	80.00% (16)	36.36% (4)	**18.18% (2)**	50.00% (3)	100.00% (4)	44.44% (4)
No	29.74% (163)	31.25% (85)	30.00% (78)	**20.36% (56)**	**41.55% (59)**	38.00% (19)	20.00% (4)	63.64% (7)	**81.82% (9)**	50.00% (3)	0.00% (0)	55.56% (5)
Had all three choices												
Yes	54.66% (293)	**59.78% (162)**	**49.43% (131)**	**71.17% (195)**	**34.27% (49)**	58.33% (28)	30.77% (8)	25.00% (3)	**0.00% (0)**	33.33% (2)	100.00% (4)	22.22% (2)
No	45.34% (243)	**40.22% (109)**	**50.57% (134)**	**28.83% (79)**	**65.73% (94)**	41.67% (20)	69.23% (18)	75.00% (9)	**100.00% (10)**	66.67% (4)	0.00% (0)	77.78% (7)

Note. Bold = statistically significant difference ($p < 0.05$ or less).

TABLE 5

Rank of Top Ten Priorities When Selecting a Home

		Participant Group		Current Setting								
Top priorities	Across participants	People with I/DD	Family members of people with I/DD	Own home or apartment	Supervised group home or apartment	Home of a family member	Planned community or campus where only people with I/DD live	Institution, including ICFs and nursing homes	Home of a friend	School dormitory	Host home	Other
Safety, security, and freedom from crime	1	3	1	2	6	5	1	4	2		6	2
Cost	2	1	6	1		2		7	1	3		7
Location	3	2	5	3	5	3	5	6	7	1		7
Close to family	3	6	2	5	3	1	10	2	7	6	1	7
Quality of services and supports	5		3		2	6	4	1	3	3	5	1
Close to shopping, places of worship, libraries, doctors, restaurants, etc.	6	4	9	4	10			7	3	9		3
Quality and stability of staff	7		4		1		1	4		8		
Close to work, school, day services, and/or services	8	6	8	7		4		7	7	1	6	3
Transportation	9	5	10	6		7			3			3
Activities and things to do	10		7		7	7	1	3		3	1	7
Accessibility		10		10					7	9		
Clean					9			7				
Culture of respect											6	
Family involvement								7				
Food									7	9		
House rules (lack of)											6	
In the community or go to the community									7			7
Independence												7
Near friends/romantic partners or ability to make							10	7	7	6	6	3
Neighborhood		8		9		7			7		6	
Neighbors											6	
Nice home in good condition		9		10	8		6	7			6	7
Own bathroom										9	6	
Own home or apartment									7	9		
Own room										9	1	
Pets									7		1	
Physical size or space				8		7		7	7			
Roommates and housemates					4				3			
Sense of community							6			9	6	
Sustainability of placement							9					
Walkable or walking distance										9		
With similar peers							8					

Note. Columns with duplicates of the same number are as a result of ties.

TABLE 6a

Satisfaction with Current Setting

		Participant Group % (*n*)		Current Setting % (*n*)									Choose where to live % (*n*)	
Satisfaction	Across participants % (*n*)	People with I/DD	Family members of people with I/DD	Own home or apartment	Supervised group home or apartment	Home of a family member	Planned community or campus where only people with I/DD live	Institution, including ICFs and nursing homes	Home of a friend	School dormitory	Host home	Other	Yes	No
Very happy	45.14% (274)	42.30% (129)	48.01% (145)	47.39% (145)	44.87% (70)	37.10% (23)	**72.41%** **(21)**	7.69% (1)	15.38% (2)	25.00% (2)	60.00% (3)	60.00% (6)	**56.51%** **(165)**	**32.64%** **(79)**
Somewhat happy	27.34% (166)	24.92% (76)	29.80% (90)	24.18% (74)	34.62% (54)	32.26% (20)	17.24% (5)	46.15% (6)	23.08% (3)	12.50% (1)	20.00% (1)	10.00% (1)	23.63% (69)	33.06% (80)
Not unhappy or happy	7.58% (46)	9.18% (28)	5.96% (18)	8.17% (25)	5.77% (9)	9.68% (6)	0.00% (0)	7.69% (1)	15.38% (2)	25.00% (2)	0.00% (0)	10.00% (1)	5.48% (16)	9.50% (23)
Somewhat unhappy	9.88% (60)	9.84% (30)	9.93% (30)	9.15% (28)	8.33% (13)	9.68% (6)	6.90% (2)	23.08% (3)	30.77% (4)	37.50% (3)	0.00% (0)	10.00% (1)	**4.79%** **(14)**	**14.05%** **(34)**
Very unhappy	10.05% (61)	**13.77%** **(42)**	**6.29%** **(19)**	11.11% (34)	6.41% (10)	11.29% (7)	3.45% (1)	15.38% (2)	15.38% (2)	0.00% (0)	20.00% (1)	10.00% (1)	9.59% (28)	10.74% (26)

Note. Bold = statistically significant difference ($p < 0.05$ or less).

TABLE 6b

Satisfaction with Current Setting by Participant Group and Setting

	Own home or apartment % (*n*)		Supervised group home or apartment % (*n*)		Home of a family member % (*n*)		Planned community or campus where only people with I/DD live % (*n*)		Institution, including ICFs and nursing homes % (*n*)		Home of a friend % (*n*)		School dormitory % (*n*)		Other % (*n*)	
Satisfaction	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members
Very happy	46.67% (91)	48.65% (54)	41.67% (45)	46.88% (45)	23.08% (3)	40.82% (20)	**16.67% (1)**	**86.96% (20)**	0.00% (0)	11.11% (1)	11.11% (1)	25.00% (1)	33.33% (1)	20.00% (1)	60.00% (3)	60.00% (3)
Somewhat happy	21.03% (41)	29.73% (33)	33.33% (20)	35.42% (34)	30.77% (4)	32.65% (16)	**66.67% (4)**	**4.35% (1)**	25.00% (1)	55.56% (5)	33.33% (3)	0.00% (0)	0.00% (0)	20.00% (1)	20.00% (1)	0.00% (0)
Not unhappy or happy	9.23% (18)	6.31% (7)	5.00% (3)	6.25% (6)	23.08% (3)	6.12% (3)	0.00% (0)	0.00% (0)	0.00% (0)	11.11% (1)	22.22% (2)	0.00% (0)	33.33% (1)	20.00% (1)	20.00% (1)	0.00% (0)
Somewhat unhappy	9.74% (19)	8.11% (9)	10.00% (6)	7.29% (7)	7.69% (1)	10.20% (5)	16.67% (1)	4.35% (1)	25.00% (1)	22.22% (2)	11.11% (1)	75.00% (3)	33.33% (1)	40.00% (2)	0.00% (0)	20.00% (1)
Very unhappy	13.33% (26)	7.21% (8)	10.00% (6)	4.17% (4)	15.38% (2)	10.20% (5)	0.00% (0)	4.35% (1)	50.00% (2)	0.00% (0)	22.22% (2)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	20.00% (1)

Note. Bold = statistically significant difference ($p < 0.05$ or less).

TABLE 7

Frequency of Moving to Different Homes

		Participant Group % (*n*)		Current Setting % (*n*)									Choose where to live % (*n*)	
Frequency	Across participants % (*n*)	People with I/DD	Family members of people with I/DD	Own home or apartment	Supervised group home or apartment	Home of a family member	Planned community or campus where only people with I/DD live	Institution, including ICFs and nursing homes	Home of a friend	School dormitory	Host home	Other	Yes	No
More often than once a year	1.86% (10)	1.52% (4)	2.20% (6)	0.37% (1)	3.55% (5)	1.89% (1)	0.00% (0)	0.00% (0)	**20.00%** **(2)**	0.00% (0)	0.00% (0)	0.00% (0)	1.81% (5)	1.70% (4)
Once a year	4.84% (26)	6.44% (17)	3.30% (9)	5.97% (16)	2.84% (4)	7.55% (4)	0.00% (0)	9.09% (1)	0.00% (0)	14.29% (1)	0.00% (0)	0.00% (0)	3.25% (9)	6.81% (16)
Once every 1-5 years	20.48% (110)	24.24% (64)	16.85% (46)	22.39% (60)	17.73% (25)	11.32% (6)	7.14% (2)	18.18% (2)	**60.00%** **(6)**	57.14% (4)	40.00% (2)	30.00% (3)	18.05% (50)	24.68% (58)
Once every 6-10 years	13.78% (74)	17.80% (47)	9.89% (27)	15.30% (41)	14.18% (20)	3.77% (2)	25.00% (7)	9.09% (1)	10.00% (1)	0.00% (0)	20.00% (1)	0.00% (0)	14.80% (41)	11.91% (28)
Less often than every 10 years	29.42% (158)	26.14% (69)	32.60% (89)	27.99% (75)	28.37% (40)	33.96% (18)	32.14% (9)	54.55% (6)	10.00% (1)	28.57% (2)	20.00% (1)	50.00% (5)	29.24% (81)	29.79% (70)
Never	29.61% (159)	**23.86%** **(63)**	**35.16%** **(96)**	27.99% (75)	33.33% (47)	41.51% (22)	35.71% (10)	9.09% (1)	0.00% (0)	0.00% (0)	20.00% (1)	20.00% (2)	32.85% (91)	25.11% (59)

Note. Bold = statistically significant difference ($p < 0.05$ or less).

TABLE 8a

Future Choices

		Participant Group % (*n*)		Current Setting % (*n*)								
Future choices	Across participants % (*n*)	People with I/DD	Family members of people with I/DD	Own home or apartment	Supervised group home or apartment	Home of a family member	Planned community or campus where only people with I/DD live	Institution, including ICFs and nursing homes	Home of a friend	School dormitory	Host home	Other
Don't have a choice	17.83% (87)	16.47% (41)	18.47% (46)	15.04% (37)	23.20% (29)	20.41% (10)	8.70% (2)	30.00% (3)	10.00% (1)	28.57% (5)	0.00% (0)	22.22% (2)
Could choose new roommate	29.30% (143)	28.92% (72)	29.71% (71)	25.20% (62)	**41.60%** **(52)**	12.24% (6)	**60.87%** **(14)**	20.00% (2)	30.00% (3)	28.57% (2)	25.00% (1)	11.11% (1)
Could choose new room	23.57% (115)	25.30% (63)	21.76% (52)	19.51% (48)	29.60% (37)	12.24% (6)	**56.52%** **(13)**	20.00% (2)	40.00% (4)	0.00% (0)	25.00% (1)	44.44% (4)
Could choose new housing type	57.17% (280)	57.32% (143)	57.43% (137)	58.94% (145)	54.40% (68)	59.18% (29)	60.87% (14)	50.00% (5)	60.00% (6)	42.86% (3)	75.00% (3)	44.44% (4)
Could choose new neighborhood	51.43% (251)	**56.22%** **(140)**	**46.44%** **(111)**	**59.76%** **(147)**	**40.00%** **(50)**	55.10% (27)	30.43% (7)	50.00% (5)	50.00% (5)	14.29% (1)	50.00% (2)	44.44% (4)
Could choose other	1.02% (5)	0.80% (2)	1.26% (3)	1.63% (4)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	**14.29%** **(1)**	0.00% (0)	0.00% (0)

Note. People could select multiple choices. Bold = statistically significant difference ($p < 0.05$ or less).

TABLE 8b

Future Choices by Participant Group and Setting

	Own home or apartment % (*n*)		Supervised group home or apartment % (*n*)		Home of a family member % (*n*)		Planned community or campus where only people with I/DD live % (*n*)		Institution, including ICFs and nursing homes % (*n*)		Home of a friend % (*n*)		School dormitory % (*n*)		Other % (*n*)	
Satisfaction	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members
Don't have a choice	14.74% (23)	15.56% (14)	16.67% (8)	27.27% (21)	**41.67%** **(5)**	**13.51%** **(5)**	16.67% (1)	5.88% (1)	33.33% (1)	28.57% (2)	12.50% (1)	0.00% (0)	33.33% (1)	25.00% (1)	0.00% (0)	40.00% (2)
Could choose new roommate	23.08% (36)	28.89% (26)	**56.25%** **(27)**	**32.47%** **(25)**	8.33% (1)	13.51% (5)	**16.67%** **(1)**	**76.47%** **(13)**	33.33% (1)	14.29% (1)	37.50% (3)	0.00% (0)	33.33% (1)	25.00% (1)	25.00% (1)	0.00% (0)
Could choose new room	22.44% (35)	14.44% (13)	37.50% (18)	24.68% (19)	8.33% (1)	13.51% (5)	**16.67%** **(1)**	**70.59%** **(12)**	33.33% (1)	14.29% (1)	37.50% (3)	50.00% (1)	0.00% (0)	0.00% (0)	75.00% (3)	20.00% (1)
Could choose new housing type	57.05% (89)	62.22% (56)	62.50% (30)	49.35% (38)	50.00% (6)	62.16% (23)	50.00% (3)	64.71% (11)	33.33% (1)	57.14% (4)	50.00% (4)	100.00% (2)	33.33% (1)	50.00% (2)	75.00% (3)	20.00% (1)
Could choose new neighborhood	63.46% (99)	53.33% (48)	45.83% (22)	36.36% (28)	33.33% (4)	62.16% (23)	**66.67%** **(4)**	**17.65%** **(3)**	33.33% (1)	57.14% (4)	37.50% (3)	100.00% (2)	0.00% (0)	25.00% (1)	50.00% (2)	40.00% (2)
Could choose other	1.30% (2)	2.20% (2)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	25.00% (1)	0.00% (0)	0.00% (0)

Note. Bold = statistically significant difference ($p < 0.05$ or less).

TABLE 9a

People's Dream Homes

		Participant Group % (*n*)		Current Setting % (*n*)								
Dream home	Across participants % (*n*)	People with I/DD	Family members of people with I/DD	Own home or apartment	Supervised group home or apartment	Home of a family member	Planned community or campus where only people with I/DD live	Institution, including ICFs and nursing homes	Home of a friend	School dormitory	Host home	Other
Own home or apartment	61.99% (256)	**78.92%** **(148)**	**47.79%** **(108)**	**85.86%** **(164)**	**39.64%** **(44)**	57.45% (27)	**17.86%** **(5)**	33.33% (3)	57.14% (4)	66.67% (4)	40.00% (2)	14.29% (1)
Supervised group home or apartment	14.29% (59)	**4.86%** **(9)**	**22.12%** **(50)**	**2.09%** **(4)**	**39.64%** **(44)**	10.64% (5)	0.00% (0)	33.33% (3)	0.00% (0)	16.67% (1)	0.00% (0)	28.57% (2)
Home of a family member	11.86% (49)	10.27% (19)	13.27% (30)	7.33% (14)	14.41% (16)	**27.66%** **(13)**	3.57% (1)	22.22% (2)	28.57% (2)	0.00% (0)	0.00% (0)	14.29% (1)
Planned community or campus where only people with I/DD live	7.99% (33)	**2.70%** **(5)**	**12.39%** **(28)**	**3.14%** **(6)**	4.50% (5)	0.00% (0)	**78.57%** **(22)**	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)
Institution, including ICFs and nursing homes	0.48% (2)	0.00% (0)	0.88% (2)	0.52% (1)	0.00% (0)	0.00% (0)	0.00% (0)	**11.11%** **(1)**	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)
Home of a friend	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)
School dormitory	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)
Host home	1.21% (5)	2.16% (4)	0.44% (1)	0.00% (0)	1.80% (2)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	**60.00%** **(3)**	0.00% (0)
Other	2.18% (9)	1.08% (2)	3.10% (7)	1.05% (2)	0.00% (0)	4.26% (2)	0.00% (0)	0.00% (0)	14.29% (1)	16.67% (1)	0.00% (0)	**42.86%** **(3)**

Note. Bold = statistically significant difference ($p < 0.05$ or less).

TABLE 9b

People's Dream Homes by Participant Group and Setting

	Current home															
	Own home or apartment % (*n*)		Supervised group home or apartment % (*n*)		Home of a family member % (*n*)		Planned community or campus where only people with I/DD live % (*n*)		Institution, including ICFs and nursing homes % (*n*)		Home of a friend % (*n*)		School dormitory % (*n*)		Other % (*n*)	
Dream home	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members	People with I/DD	Family members
Own home or apartment	**91.23% (104)**	**77.92% (60)**	50.00% (19)	34.25% (25)	81.82% (9)	50.00% (18)	**66.67% (4)**	**4.55% (1)**	50.00% (1)	28.57% (2)	80.00% (4)	0.00% (0)	100.00% (2)	50.00% (2)	50.00% (1)	0.00% (0)
Supervised group home or apartment	0.88% (1)	3.90% (3)	**18.42% (7)**	**50.68% (37)**	0.00% (0)	13.89% (5)	0.00% (0)	0.00% (0)	50.00% (1)	28.57% (2)	0.00% (0)	0.00% (0)	0.00% (0)	25.00% (1)	0.00% (0)	40.00% (2)
Home of a family member	5.26% (6)	10.39% (8)	**26.32% (10)**	**8.22% (6)**	18.18% (2)	30.56% (11)	16.67% (1)	0.00% (0)	0.00% (0)	28.57% (2)	**0.00% (0)**	**100.00% (2)**	0.00% (0)	0.00% (0)	0.00% (0)	20.00% (1)
Planned community or campus where only people with I/DD live	2.63% (3)	3.90% (3)	2.63% (1)	5.48% (4)	0.00% (0)	0.00% (0)	**16.67% (1)**	**95.45% (21)**	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)
Institution, including ICFs and nursing homes	0.00% (0)	1.30% (1)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	14.29% (1)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)
Home of a friend	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)
School dormitory	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)
Host home	0.00% (0)	0.00% (0)	2.63% (1)	1.37% (1)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)
Other	0.00% (0)	2.60% (2)	0.00% (0)	0.00% (0)	0.00% (0)	5.56% (2)	0.00% (0)	0.00% (0)	0.00% (0)	0.00% (0)	20.00% (1)	0.00% (0)	0.00% (0)	25.00% (1)	50.00% (1)	40.00% (2)

Note. Bold = statistically significant difference ($p < 0.05$ or less).

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